AN ASSESSMENT AND REVIEW OF CURRENTLY EXISTING DATABASES AS A FOUNDATION FOR THE MONITORING OF HEALTH STATUS OF A POPULATION WITHIN A DEFINED GEOGRAPHIC LOCATION

MARGARET J. WEBB

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An Assessment and Review of Currently Existing Databases as a Foundation for the Monitoring of Health Status of a Population Within a Defined Geographic Location

by

Margaret J. Webb

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ABSTRACT

The purpose of this study was to first determine the availability of health status monitoring models within the community health arena. An assessment was then made as to the availability, quality and accessibility of existing health and social indicator data sources relevant to Labrador Inuit. To investigate the quality and practicality of the data sources, a conceptual and analytical framework was developed from a review of the concepts of measurement, measurement tools and health status indicator selection. Following this investigative process, a data collection model was proposed that could be used over time within the region of interest, utilizing components of the data and information sources inventory.

The evidence from this thesis indicates that a great deal of information exists about the population of concern. This information can be used to measure health status. As well, a number of excellent tools have been developed to measure population health; one of these tools can be adapted to fits regional needs at this time. The thesis concludes by making a number of recommendations for supporting the development of a comprehensive health status monitoring instrument for a small population.

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CHAPTER ONE: A Beginning

1.0 Introduction

Northern Labrador, home to some 4,800 Inuit, recently became the focus of a major mining exploration and development project at Voisey's Bay. As local health care agencies reviewed the Environmental Impact Statement (EIS) and sought to describe the health status of the people, the pending development further accentuated an already pressing need for adequate health information. Historically, health information has been sporadically gathered by health care and social service organizations within the region for administrative purposes, but has not been generally analyzed or shared. This mining development heightened awareness of the need for a health monitoring tool, data base and health information system that can be used as a means to appropriately assess the general health status of the population pre-development, during subsequent stages of the project and overall.

Community health workers are constantly in need of information on the prevalence of risk factors and health problems in small populations, defined geographically or otherwise, but adequate information is rarely available. However, within the Labrador region, a Regional Health Survey (LIRHS) was conducted by the Labrador Inuit Health Commission (LIHC) in the spring of 1997 which could provide baseline data for a health status assessment of the population. The results of this survey, plus an adequate community health status monitoring tool, could be effectively utilized to estimate the prevalence of selected risk factors and health status indicators in this relatively small population. This comprehensive data would then become the evidence base for a health information system that would be used to plan and allocate health care resources based on population health needs (Bergner and Rothman, 1987; CDC, 2000). A health status monitoring tool and system is needed that can generally oversee health effects.

The major focus of such a system would be to describe the patterns of health of the residents in the Northern Labrador region. This population based approach would be fundamentally different from analyses that focus on descriptions of specific illness treated in hospitals or by physicians. It is expected that a comprehensive community heath monitoring tool and information system would be generally accepted and consistently applied and reported over time (Roos, 1995). Although there are a number of sources of information that report various indicators of health status, they tend to be reported intermittently and independently and are often used for ad hoc purposes. The absence of a widely accepted health monitoring system, especially at the community and regional level, allows health problems and priorities in our communities to be defined by the managerial objectives of our health institutions and agencies, the existing maze of mandated categorical funding, and the resultant political agendas rather than by any form of comprehensive, objective appraisal.

A major challenge for health policy makers is to identify and implement methods of resource planning and allocation based on health evidence generated within an area of concern (Alberta Health, 1995). It would seem that meeting this challenge is also consistent with the primary objective of Canadian health policy (as enshrined in the Canada Health Act 1984) which is to protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers (Birch and Eyles, 1991). The intent of such a comprehensive profile would be to help the community to establish and maintain a broad strategic view of its health status and the various factors that influence it (Gosselin et al, 1993).

1.1 **Health Status Indicators**

Health status indicators describe the state of health and well-being of a population. They are markers or signs of something to be measured but which may not be directly, fully or

easily measured. For example, population health status is a qualitative and complex concept, and life expectancy, infant mortality, and similar measures are generally used to describe or indicate the health status of the population (Alberta Health, 1995). Indicators also provide information needed for specifying objectives or desired results, for tracking progress toward goals (i.e. performance measures), and for assessing the appropriateness of services (American Public Health Association, 2000).

1.1.1 The Importance of Socioeconomic Indicators

There is a growing interest in Canada, generated in part by the Black Report (Townsend, et al, 1992), in health status and its socioeconomic correlates. Studies have identified strong relationships between health variables (mortality, morbidity, self-reported health status) and various socio-economic variables. Using data from the Canada Health Survey, Hay found a direct positive relationship in adult non-elderly populations between health status (individual self-reports on disability days, oxygen consumption, skin-fold measures) and socioeconomic factors (education, income, occupation), with the income-health correlation being the strongest (Hay, 1988). Roos and Shapiro found a similar relationship between income and self-reported health from the elderly in Manitoba (Roos and Shapiro, 1981). Both the length (Wigle and Mayo, 1980) and the quality (Wilkins and Adams, 1983) of life of the elderly have been shown to correlate well with income.

More recently Wilkins observed strong negative correlations between family income and both mortality and disability in children (Wilkins, 1990), and Wilkins et al showed that despite decreases in the differences in life expectancy at birth between the highest and lowest income quintiles between 1971 and 1986, relative mortality (lowest compared to highest income quintile) at most ages changed only slightly over this period (Wilkins, 1990). Furthermore, the socioeconomic differences are found to persist even after controlling for age, race, gender, baseline health status, depression and certain lifestyle behaviors such as smoking, alcohol consumption and physical activity (Hertzman, 1990).

In terms of risks to health, Millar showed that after adjusting for age and gender, the prevalence of smoking was highest among persons with little education (Millar, 1987). while Wilkins found a positive relationship between knowledge of the health risks associated with smoking and education (Wilkins, 1988). Risks of ill-health, in the form of incidence of unfavorable birth outcomes (low birthweight, prematurity, and small size for gestational age) were found to be strongly and consistently related to the percentage of low-income families in the area of residence (Wilkins et al, 1991). Saveland and Gillieson found low education, low income levels and job interruptions and demand were all associated with higher mortality risks (Saveland and Gillieson, 1971). Specific relationships have been examined by other researchers, for example, poorer health status or life expectancy has been observed among aboriginal Canadians (D'Arcy, 1989), among the unemployed (D'Arcy and Siddique, 1985), and in rural areas (Wilkins and Adams, 1983), while persons whose native tongue is other than English or French were less likely to be happy, have poorer self-rated health, more activity limitation, and more negative attitudes to diet and nutrition (Wilkins, 1988; Adams and Wilkins, 1988).

Roos suggests that with the movement away from the traditional medical model of health towards one which recognizes the wide range of influences, both societal and individual, on health status, needs for health care cannot be measured in terms of levels of health status alone. Because health care is not provided as an end in itself, but as a means to producing improvements in health status or health-related quality of life, the *need* for health care is not the same as the presence of morbidity. The need for health care is interpreted in terms of ability to benefit from health care as implied by reducing the risks of deterioration in health status (or health-related quality of life) or improving the probability of improvements to health status (or health-related quality of life). Thus an important distinction is introduced between indicators of *health status* and indicators of *need for health care* (Roos, 1995).

In questioning the potential of alternative indicators of health status for the purposes of allocating health care resources among populations then, there is less concern with how well the indicator represents between-population differences in health status per se, and more concern with how well it represents between-population differences in conditions and health risks which are amenable to health-care provision. This means that there is a need to be concerned with the properties and applicability of the indicators used (Roos, 1995). Thus for aboriginal people, it would seem that health status and its socioeconomic correlates will be entirely applicable and useful as an attempt is made to develop a health status monitoring tool.

1.2 A Brief Summary of Socioeconomic Indicators of Health Status in Aboriginal Communities

The 1991 Aboriginal Peoples Survey (APS) (Statistics Canada 1993a, 1993b, 1993c) provides a snapshot of the general conditions of life for Aboriginal people; characteristically, such data are very general. The data resulting from the Labrador Inuit Regional Health Survey (LIRHS) conducted in 1997 are much more specific to our region and are useful for comparison purposes. To understand the health issues which our people currently face, and the prospects for change in health and social status, one must appreciate the significance of various socioeconomic factors.

Demographically, the Aboriginal population is quite young: 38 % were under the age of fifteen, giving a dependency ratio of only 1.6 adults per child. Approximately 39% of Labrador Inuit are under the age of 18. In terms of education, in the fifteen to forty-nine year age bracket, 50% of those surveyed in the APS reported having completed secondary school, while 3% reported having completed a university degree. Some 17% had completed less than grade 9. The LIRHS showed education levels varying widely in the communities of concern. Eighteen percent of adults had less than a grade six education, but 23% of the population reported having completed high school. Thirty-

three percent of the Aboriginal people surveyed under APS reported at least some post-secondary education experience, as compared to 8% of Labrador Inuit; the figure for Canadians nationally was 51%.

Another socioeconomic indicator important to consider is that of employment levels. In Canada overall, the unemployment rate for Aboriginal people was almost 25%, compared with around 10% for Canadians in general; the labor force participation rate for Aboriginal people was 57%, compared with 68% nationally. The highest unemployment rates were noted in Newfoundland and Labrador (44.3%) and the Yukon (35.4%), with the lowest in Ontario (17.1%) and Alberta (23.%). Forty-five percent of adults were working for pay at the time of delivering the LIRHS, while 74% worked at some time in the past year. Twenty-one percent were looking for work, while the remainder were homemakers (17%), going to school (3%) or retired (8%). However, these data mask the consequences of living in remote and rural areas. For instance, in some northern Aboriginal communities, the unemployment rate reaches as high as 90% at various times throughout the year. In many communities, seasonal employment in wage labor or activities such as commercial fishing, trapping, or general labor tasks are often followed by long periods of unemployment and hardship.

Reported income levels are lower for Aboriginal people. For instance, while 45% of the APS respondents reported an annual income in 1990 of less than $10,000, 35% of Canadians as a whole reported likewise (this also includes individuals who reported earning no income). And while 15% of Canadians reported an income in excess of $40,000, 5% of Aboriginal people did as well. But, as is the case with most socio-economic variables, there are significant discrepancies when examining specific Aboriginal categories. For instance, on reserve First Nations and Inuit exhibit the highest proportion of income earners reporting less than $10,000 in annual income (65% and 57%, respectively); the proportion is lower among off reserve First Nations people (50%) and Metis (49%). The LIRHS showed 25% of adults lived in a household where the

income was less than $10,000. On the other hand, 26% of adults lived in a household with an income of $25,000 or more.

Housing and infrastructure problems are invariably related to many of the health challenges people experience. In general, housing and living conditions of Aboriginal people have consistently been poor and below national standards. Despite many initiatives by both federal and provincial governments to provide electricity, proper sewage disposal, potable water and better quality housing, discrepancies still exist. The 1991 APS (Canada, DNHW 1994) reported a higher than average number of persons per dwelling and persons per room in Aboriginal households than in households nationally. While 32% of homes nationally required either minor or major repairs, 49% of Aboriginal households were in need of repair. Labrador Inuit reported identified inadequate housing as a priority issue in the LIRHS.

This brief summary is evidence that the general health and well-being of Canada's Aboriginal people in general, and Labrador Inuit in particular, cannot help but be greatly influenced by the social health of the communities in which they live.

1.3 **Population Health Status - Beginning Steps**

Data from the APS and other national surveys do not provide enough information when assessing health status for decision making at the community and regional level. The overall socioeconomic data are useful for between-group comparison purposes, but sampling numbers are small per group (at times only one or two people/ community have been surveyed under APS) and the survey is generally intended for use nationally, rather than at the community or regional level where actual health care allotment decisions are made. Spasoff suggests that national surveys have inadequate sample size to provide stable estimates for small populations (Spasoff et al, 1996). But survey instruments from APS may be useful to integrate into the chosen database for the region.

During the past several years, nine (9) Aboriginal groups from across Canada gathered baseline data to begin to monitor the health of their various populations (the Labrador region being the only Inuit group participating), through the process of a number of nationally coordinated regional health surveys. Most groups in the country had not, in the past, had the resources or capacity to develop and conduct surveys of this nature. Although Young et al did complete the Keewatin Health Study in 1990 and gathered baseline data for the Keewatin Health Board pre transfer, this study was largely medically oriented and produced a great deal of data to describe the health status of the people of that region.

Thus, all participating regions had an extreme need for their own health data - data that were collected, compiled and analyzed by and for Aboriginal people. The information was collected, primary analysis was completed and the various resulting data sets will form the foundation for health status monitoring capability within Aboriginal Canada.

The Labrador region now seeks to add to this database by developing a health status monitoring tool utilizing one of, or components of, those outlined in the forthcoming literature review. It would seem that population-based information is essential to helping organizations ask the right questions. When poor health status is found among high-risk, low-income groups such as those in our region, the tendency has been to assume that the primary need is for more health services. Without information demonstrating that access to services or care in these communities (at least in a universally insured and funded system) is adequate or inadequate, it is difficult to shift the discussion to other interventions that might make a greater impact on health.

Roos proposes that when one looks at high-use patterns, particularly at the high rates of hospitalization for medical conditions, the first question that really needs to be asked is: What are the socioeconomic risk characteristics of the high-use population? It may well

be that the high use rates reflect high need, and that residents of low-use regions overuse hospital resources when their socioeconomic status is taken into account (Roos, 1995).

1.4 **Health Care Delivery Within the Region of Interest**

The Labrador Inuit Region is located within the province of Newfoundland and Labrador. Four thousand eight hundred (4,800) Inuit are located in the northernmost part of Labrador in five coastal communities, with significant membership located in the central Labrador region. This population is represented politically by the Labrador Inuit Association (LIA), which operates under the direction of an elected President and Vice-President, who are accountable to an elected Board of community Directors. The Labrador Inuit Health Commission (LIHC) is the health care affiliate of LIA, formed in 1985 to look after the health concerns of its membership.

A brief description of the health care service providers that exist within the region is as follows:

a) **Labrador Inuit Health Commission (LIHC).** LIHC is funded by First Nations and Inuit Health Services (FNIHS) of Health Canada to deliver a substantial number of core health education and promotion programs. (It should be noted that many of these programs would not be otherwise offered in the region and/ or are a further enhancement to programs being offered by the provincial health care system.) Programs and services include: Community Public Health Nursing services (transferred from the province in March 1997). the Community Health Worker program, Non-Insured Health Benefits (NIHB), Dental Therapy Services, Addictions Prevention and Treatment, Home Support Services, Mental Health Services at the community level, Health Referral Liaison, Youth Programming, Aboriginal Head Start, Child Development Programs, program related research and so on.

b) **Provincial Health Care**. The province of Newfoundland and Labrador, Department of Health and Community Services (DOHCS), is directly responsible for health care and delivers primary care services to this part of the province through a regional organization known as Health Labrador Corporation (HLC). This agency offers health care through Nursing Stations in all coastal communities, some limited Mental Health Services at the

regional level, laboratory services, an air ambulance service, visiting dental services, visiting physician services, home care services, as well as program related research. These services are overseen by provincial administrative staff, who are in turn responsible through a Chief Executive Officer (CEO), to a regional politically appointed Board of Directors.

Some Physician Specialty services are provided through Health Labrador Corporation on-site in Goose Bay (i.e., obstetrical services), while others are available on a visiting-physician-basis. Those services that are not provided within the region must be accessed by travel to other centers on the island portion of the province, such as St. Anthony or St. John's. Coastal residents must travel at least to Goose Bay to access specialty services.

Dental services to coastal communities are contracted to private dentists through Health Labrador Corporation. These services are delivered in the local Nursing Stations on a somewhat regular basis (i.e., every six weeks to eight weeks).

c) **Social Services** are delivered through the provincial Department of Health and Community Services as the result of an amalgamation process in April 1999. Staff with this particular focus provide some health related services as well, for example:
   - Various health related services are provided to social assistance recipients for which the provincial hospital and medical care insurable programs do not pay;
   - Limited programs for emotionally and physically challenged children and adults are provided;
   - Vocational rehabilitation services for individuals having difficulty obtaining and retaining suitable employment because of health problems are also undertaken.

   As well, social program staff supply/ finance child welfare services, respite care, child day care centers, and limited programs for the aged. They also provide financial assistance for the needy and their dependents.

d) **Medical Care Insurance** (MCP) is available to the entire population of the province of Newfoundland and Labrador. A number of health care services are covered by this plan. The Non-Insured Health Benefits (NIHB) program provides other services to Labrador Inuit that are not included in the MCP plan.

e) **Environmental Health** is delivered on a limited basis through the provincial department of Government Services and Lands. This department usually employs a Health Inspection Officer who is expected to provide service to the entire Labrador region. The Labrador Inuit Health Commission's (LIHC's) Community Health Workers liaise with the Health Inspection Officer around the issues of safe drinking water, food and adequate water and sewer systems. LIHC has included enhanced Environmental Health in its five year Community Health Plan (CHP).

f) **Occupational Health and Safety** services are available through the provincial department of Environment and Labor, Workplace Health and Safety Branch. This department is represented in the region by an office in Labrador City. Health and Safety concerns and information seeking can also be undertaken using a toll-free number to the St. John's office. This office is the regional link to the Work Place Health and Safety Compensation Commission.

This then is the existing health service delivery climate in which the development of a health status monitoring tool for the population of concern is proposed. A climate in which there are a number of parallel health care deliverers, where health and the outcomes of health betterment initiatives are in need of ongoing monitoring and review. A climate that would seem ripe for the development of new initiatives, for cooperative undertakings, and information sharing which benefits clients and concerned health care providers alike.

1.5 **Thesis Purpose and Objectives**

The purpose of this thesis was first to determine the availability of health status monitoring models within the field of Community Health. An assessment was then made as to the availability, quality and accessibility of existing health and social indicator data sources. A conceptual and analytical framework was also developed to investigate the data source inventory and its utility within the chosen model. Following this investigation, the researcher proposed a data collection model that can be used over time

within the region of interest, utilizing components of the data and information sources inventory.

It was hypothesized that a great deal of information is already collected at the community, regional and national levels relevant to Labrador Inuit. The review and subsequent suggested methods for coordination and organization of this data, with adjustments for informational gaps, could result in the development of an acceptable health status monitoring tool.

Specifically, the objectives of this study were to:

a) Conduct a literature review to determine the availability of health status monitoring models;
b) Conduct an inventory of existing health and social indicator databases and information sources applicable to the region;
c) Review and describe these databases, utilizing a standard set of criteria, as a foundation for the development of a health status monitoring system; and
d) Propose a health status monitoring tool/ model for the population of interest.

The development of a health status monitoring system for the region of interest is proposed for several reasons, those being:

a) to describe the patterns of health of residents within the region;
b) to appraise and evaluate the effectiveness of health programs and services;
c) to measure the impact of external influences, such as the proposed development of a mine/ mill project, on the health of the residents.

1.6 **Research Questions**

In keeping with the above noted objectives, three research questions guided the direction of this project:

1. How can the health status of the population of concern be most effectively measured, utilizing currently existing data sources? Can these data sources be modified or adapted to fit regional needs?

2. Are there additional measures that do not exist or are currently incomplete? How can the collection of these additional data be ensured?

3. Can a health status monitoring tool be proposed for the population of interest as the basis for a monitoring system? Will this mean the development of a new tool or the adaptation of a currently utilized population health tool?

1.7 **Organization of the Thesis**

This thesis is organized into eight chapters describing and assessing the components of data sources currently collected on and about Labrador Inuit. Chapter Two reviews the literature relevant to health status monitoring, focusing on models that have been developed within community health. Chapter Three outlines the conceptual and analytical framework used in the study. Chapter Four outlines the methods/ steps undertaken to move from a health status measuring model to a practical tool that can be used to measure health status. Chapter Five describes the identified data sources. In Chapter Six, the results of the inventory are analyzed according to criteria established in the conceptual and analytical framework. Chapter Seven discusses the results of the inventory analysis. Chapter Eight outlines conclusions and recommendations for supporting the development of a comprehensive health status monitoring instrument for a small population.

CHAPTER TWO: A Review of the Literature

2.0 Introduction

A literature review was undertaken as the first step in the possible development of a health status monitoring tool. This review will commence with a definition of terms. A summary of the characteristics and capabilities of a number of population based health monitoring tools follows.

2.1 Methods

2.1.1 Information Sources

A computerized search for information on the topic of *health status measurement* was undertaken utilizing the Advanced MEDLINE database; key words for the search were "community health," "indicators" and "health status." Six hundred and sixty-five (665) references and their bibliographies were retrieved and scanned, with one-hundred and forty-two (142) being further selected for consideration and thus forming the basis for this review. Material was also identified from a review of standard community health texts and their bibliographies. Colleagues and experts in the field of Community Health were consulted and provided information and articles from their personal files.

2.2 Defining the Concepts

In the exploration of health status and the various concepts that surround the topic, it is necessary to provide definitions to clarify the purpose and context of the terms.

a) **Health** – Health as a concept is both highly intricate and very broad. It is so difficult to define that a valid and reliable assessment of health status has traditionally eluded scholars and practitioners of health and medicine (Abanobi, 1986). The difficulties in the conceptualization of health are evident in the following frequently encountered definitions of health:

> Health consists in the capacity of an organism to maintain a balance in which it may be reasonably free from undue pain, discomfort, disability or limitations of actions, including social capacity (Blum, 1977).
>
> Health exists when an organism is successfully adjusted in its environment and is able to maintain this state free of undue excitation, capable of growth, development and activity in an integrated and effective sense (Engel, 1962).
>
> Health is a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity (WHO, 1958).
>
> The extent to which an individual or group is able to realize aspirations and satisfy needs, and to change or cope with the environment. Health is a resource for everyday life, not the objective of living; it is a positive concept, emphasizing social and personal resources as well as physical capabilities (WHO, 1984).

None of these definitions of health lends the health status of individuals or aggregates of population to direct and valid measurement (Abanobi, 1986). Quite often, the terms used to define health are very relative and unclear. What, for instance is meant by *mental well-being*? Abanobi suggests that the ambiguity in the terms used to define health engender serious difficulties in the design and standardization of valid and reliable health status indicators and indices.

Differences in the conceptualization of health reflect the tendency of various schools of thought to place more emphasis on some of the many elements that comprise the concept of health than others. Thus health, as often defined, is fragmentary and non-comprehensive, lacking a balanced emphasis as in process and outcome: sickness versus wellness, individualistic versus population based approach, etc. Which perspective gets incorporated in any of the various schemas is a function of personal, cultural, and professional bias as well as technological facilitation. This bias carries over into the design of health status indicators and indices, as well as other instruments and procedures for the measurement of health status (Abanobi, 1986).

It should also be emphasized that Aboriginal people also have comprehensive definitions of health, definitions that emphasize holism and balance; with a general emphasis on physical, social, emotional and spiritual well-being. Aboriginal understandings of health also emphasize the links between health and the natural and social environment, as evidenced by the title of the Labrador Inuit Association's (LIA's) Issues Scoping Project (Williamson, 1996), "Seeing the Land is Seeing Ourselves." (This project involved a regional consultation, whereby members of LIA were asked to offer opinions as to the potential impact of a large scale development on themselves and their way of life.)

b) **Health status** - The degree to which a person is able to function physically, emotionally, socially, with or without aid from the health care system (Last, 1995).

c) **Health status indicators** – Health status indicators describe the state of health and well-being of a population. Health status should be the "bottom line" for everything we do in the health care system. That is, all planning and action should be focused on improving or maintaining health and well-being. Health status indicators make a critical contribution to effective, accountable, decision-making (Alberta Health, 1995).

d) **Determinants** - A determinant is any factor, whether it is an event, characteristic, or other definable entity, that brings about change in health condition or other defined condition (Last, 1995).

e) **Evidence-based decision making** – Evidence-based decision making is a process that takes facts, data and other evidence into account. It is an essential part of effective and accountable planning, action and evaluation. Indicators provide the basis upon which informed decisions are made (Last, 1995).

f) **Measurement** - The procedure of applying a standard scale to a variable or to a set of variables. A number of terms are utilized to describe measurement, and these are: accuracy, precision, validity, reliability, repeatability, and reproducibility (Last, 1995).

g) **Outcomes** - All the possible results that may stem from exposure to a causal factor, or from preventive or therapeutic interventions; all identified changes in health status arising as a consequence of the handling of a health problem (Last, 1995).

h) **Surveillance** – Continuous analysis, interpretation, and feedback of systematically collected data, generally using methods distinguished by their practicality, uniformity, and rapidity rather than accuracy and completeness (Eylenbosch and Noah, 1988). By observing trends in time, place and persons, changes can be observed or anticipated and appropriate action, including investigative or control measures, can be taken. Sources of data may relate directly to disease or to factors influencing disease. Thus they may include 1) mortality and morbidity reports based on death certificates, hospital records, general practice sentinels, or notifications; 2) laboratory diagnoses; 3) outbreak reports; 4) vaccine utilization – uptake and side effects; 5) sickness absence records; 6) disease determinants such as biological changes in agents, vectors or reservoirs; 7) susceptibility to disease, as by skin testing or serological surveillance (Last, 1995).

i) **Representativeness** – A surveillance system that is representative accurately describes the occurrence of a health event over time and its distribution in the population by place and person (CDC, 2000).

j) **Simplicity** – The simplicity of a surveillance system refers to both its structure and ease of operation. Surveillance systems should be as simple as possible while meeting their objectives (CDC, 2000).

k) **Acceptability** – Acceptability reflects the willingness of individuals and organizations to participate in a surveillance system (CDC, 2000).

l) **Timeliness** – Timeliness reflects the speed or delay between steps in a surveillance system (CDC, 2000).

While existing definitions tend to present health as a unitary or holistic concept, in practice it is often convenient to divide health into several domains, each with its own data source and indicators. In accordance with the Inuit definition (for the purpose of the development of our tool), these domains are: physical, mental/ emotional, social and cultural/ spiritual.

2.3 **Individual/ Subjective Health Status - Structured Measures**

Over the past thirty plus years, researchers have generated numerous tools that use self-reporting to measure functional status, emotional well-being, and subjective perceptions of health. The distinguishing purpose of these structured health measures has been to

offer insight into subjective aspects of health that cannot be ascertained from laboratory tests or population statistics. They therefore aim to record and represent, in a systematic way, aspects of health that cannot be determined from 'hard' data or morbidity statistics, but must instead rely on the judgments of individuals, whether patients or clinicians (McDowell and Newell, 1987). Data are obtained usually from self-completed questionnaires or from the observations of clinicians or therapists. Most researchers and clinicians are very familiar with the methods of natural science, and so have been relatively willing to incorporate structured, quantitative measures into clinical and survey work.

2.3.1 **Types of Health Status Measures**

The literature (McDowell and Newell, 1987; Bowling, 1991; Wilkin et al, 1992) suggests that health status measures fall into seven basic categories and include the following:

A. General Health Measures

Measures such as the Nottingham Health Profile (NHP) (Hunt and McEwen, 1985), Sickness Impact Profile (SIP) (Bergner et al, 1976), the Health Measurement Questionnaire (Kind and Gudex, 1994), and the Medical Outcomes Study Instrument SF36 (Tarlov et al, 1989) aim to provide global profiles of health, including well being, function, social and emotional health. There is also the single item global health measure which asks if the respondent rates her or his health as excellent, good, fair or poor (Segovia, Bartlett and Edwards, 1989). As well, the RAND Health Insurance Experiment was regarded as differing from other health status measures in that it did not specify one or more components of health (i.e. physical, mental or social). Rather, respondents are asked for an assessment of their health. In theory, this difference in measurement model makes it possible to tap both the objective information people have about their health status and their evaluation of that status (Ware et al, 1978).

Another attempt to develop a global index, or set of indices, of health based on self-reporting has been undertaken in the Alameda County Human Population Laboratory in California. The aim was to formulate a method of measuring health based on the WHO definition of health and to test the method in a general population. Rather crude and simple questionnaire measures of physical, mental, and social well-being were developed and applied to place the general population of Alameda County on a health continuum. The health of individuals and of subgroups in the population was also assessed by using the ridit method with this data set. For example, persons with a minor degree of disability have a state of health characterized as a 0.89; the higher the ridit the poorer the health. Measured by the ridit method, health declines with age as expected (Belloc et al, 1971).

B. Measures of Physical Function

These aim to determine levels of disability, impairment, and physical function within general populations, such as the Lambeth Disability Screening Questionnaire (Patrick et al, 1981) or for specific groups such as the elderly in residential accommodation, such as the Pulses Profile (Moskowitz, 1957). These measures focus on activities of daily living such as dressing and going up steps.

C. Pain Measures

Instruments such as the McGill Pain Questionnaire (Melzack, 1983) and visual analogue scale (Scott and Huskisson, 1979) seek to represent the intensity of pain.

D. Social Health Measures

Social health measures such as the Social Health Battery (Williams, Ware and Donald, 1981) aim to assess the strength of people's social support networks.

E. Psychological Measures

Measures such as the General Health Questionnaire (Goldberg and Hillier, 1979) identify people with psychological or psychiatric morbidity.

F. Quality of Life Measures

Examples such as the Four Single Items of Well-Being (Andrews and Crandall, 1976) and the Quality of Life Index (Spitzer et al, 1981) seek to measure the overall satisfaction and well being of individuals.

G. Specific Disease Measures

The Arthritis Impact Measurement Scale (Meenan, Gertman and Mason, 1980) and the Oswestry Low Back Pain Questionnaire (Fairbank et al, 1980) are examples. These concentrate on issues of particular importance to patients with specific diagnoses.

2.3.2 **Critique of Subjective Health Measures**

Typically, these instruments consist of established sets of closed questions which are asked in the same order and way to every individual. Questions tend to have limited numbers of responses and respondents (or clinicians) have to tick those closest to their own view. Subjective reports of health are not inherently quantitative, and so some form of rating method is required to translate statements such as 'unbearable pain' into a form suitable for statistical analysis. Rating methods and the weighting of scales have allowed health measures to take on the style of quantitative research (Streiner and Norman, 1995).

Donovan argues that structured health measures should continue to be used as the health status of the population is clearly a legitimate interest and because these measures purport

to reflect this quality. We cannot, however, evade the question of what it is that these measurements actually measure. In attempting to become an accepted part of scientific research, many instruments have become overly concerned with their ability to be reliable and valid as measured by statistical tests (Donovan et al, 1993). Subjective health then becomes a single number or set of numbers that are taken out of their context and used in policy making alongside so called 'hard' data. It remains to be seen as to what aspects of perceptual health can be reduced to such simplistic numbers. These numbers are, in any case, often derived somewhat arbitrarily. The instrument and their scores are grounded in the values of the originators, supported by apparent scientific reliability and validity (Donovan et al, 1993).

Instead of addressing these aforementioned concerns then, the debate about the measurement of health seems somewhat stuck at the level of which instrument to choose. Researchers are encouraged to choose a measure that is reported to be valid and is easy to complete (Scrivens et al, 1985). They may then be faced with a choice between very many instruments in some areas - there are, for example, 43 scales focusing on the activities of daily living (Feinstein et al, 1986). It is also the case, however, that in some areas, choice seems very constrained. Particular instruments become 'fashionable' and are used almost indiscriminately by researchers because they have been used by so many others. The consensus then holds that these instruments are valid and reliable. The NHP has replaced the SIP in much research work in this way because it is perceived to be better or more sensitive, but, more likely because it is in common use (Donovan et al, 1993). The SF-36 is now, in turn, replacing the NHP in epidemiological studies and outcome assessments as it is reported to be valid and reliable (Stewart, Hays and Ware, 1988), more so than the NHP (Brazier et al, 1992).

Health then is an extremely complex concept. It is closely related to other complex concepts such as well-being and quality of life. All of these have difficult and variable definitions which seem to have been rarely tackled in the published reports. Health status

instruments seem to offer an easy solution: the measurement of health by relatively simple instruments, thoroughly tested for reliability and validity. They are also attractive to those familiar with the methods of natural science because they produce quantitative results. The use of statistics and statistical methods have given many instruments such a sense of validity and reliability that individual researchers might make judgments based on these criteria rather than on what they actually want to measure in their studies (Donovan et al, 1993).

2.4 **Population Health Measures**

Measuring and reporting the health status of the population is crucial to any attempt to shift attention to population health from the current preoccupation with health care. While the literature provides examples of a number of successful programs to measure population health status, there is not the same wealth of information as there was on individual health status monitoring. The examples found are as follows.

Model A - POPULIS:

The Manitoba Centre for Health Policy and Evaluation has developed a Population Health Information System, known as POPULIS. This system contains 102 health status indicators, used to measure the health of Manitobans based on mortality and various conditions for which they were hospitalized or visited physicians (Cohen and MacWilliam, 1995).

The conceptual model that underpins the Population Health Information System represents a modification proposed by Evans and Stoddart, expanded to incorporate individual level effects and changes over time (Evans and Stoddart, 1990). The model provides a framework for considering the relative contribution of a number of background factors (i.e. socioeconomic factors, demographics, and genetics) to health status and population health. (Although eventually a number of key physical

environmental indicators will be incorporated into the information system, the first phase is focused primarily on the socioeconomic determinants of health.) Conversely, the model suggests that health status ultimately feeds back to influence the socioeconomic environment in which individuals operate and further influence utilization of the health care system (Roos et al, 1995).

Roos describes the steps for developing a population-based system to compare health status, various key risk indicators, and hospital use:

a) Create meaningful geographic areas.

b) For each area, obtain data for the denominator - the number of area residents and their age and sex.

c) For each area, obtain indicators of socioeconomic risk. As a first step, census data is suggested to develop indicators such as household income, unemployment, education, and cultural diversity.

d) For each area, develop indicators of health status for residents from various sources, including all-cause, cause-specific, and premature mortality rates from vital statistics files. [Although measures based on mortality might be viewed as insensitive, they have been demonstrated to track more widely accepted measures such as disease-free life expectancy more closely at the population level (Robine and Ritchie, 1991)].

e) For each area, describe the utilization of health care by area residents for each sector:

- hospital use;
- use of nursing homes;
- use of physician services.

POPULIS is designed to assess the health of the population using a variety of indicators, as well as to assess socioeconomic risk characteristics that are shown to be strongly related to the 'need' for health care. Being population based, the system tracks health care use of populations regardless of where such usage takes place, as distinct from examining

clinical care and associated outcomes for individual patients or treatments. Roos states that standardizing the age and sex characteristics of a population across geographical areas adjusts for two of the important determinants of health and use of health care.

POPULIS provides data on the supply of services (i.e. hospital beds, nursing home beds, and physicians), the usual parameters of health planning. It also directly measures access to care, focusing on the proportion of residents in a given area who receive a service - regardless of where the service is obtained.

POPULIS is organized around such issues relevant to policy-making as intensity of use. The system also permits the comparison of use patterns across regions whose residents have similar health status, allowing policy makers to come closer to understanding which usage rates are most acceptable.

POPULIS has also been organized to help managers of health care resources by selecting indicators relevant to them. For example, the hospital indicators distinguish among medical, surgical, pediatric, psychiatric, and obstetric admissions, focusing on the use that takes place in the region of residence versus out of the region.

The system permits cross-sector analyses, combining use (using dollar figures when possible) and, in the case of nursing home and hospital use, summing total days of institutional care. Finally, regional profiles can show how each region's health, socioeconomic risk, and use characteristics differ from the provincial norm.

The system can also distinguish between indicators of health status and indicators of need. This approach allows POPULIS users to determine if some populations at high socioeconomic risk (the proposed measure of health need) have better health status than other high-risk populations (possibly due to more appropriate types of health care delivery). Other systems have not made this distinction (Roos, 1995).

The data bank can be used to assess the impact of specific interventions and assess the efficiency of institutions.

The information generated by the population-based analyses would seem to present policy-makers with a challenge because it represents a major departure from the public's image of what matters and what stakeholders believe about their own effectiveness in improving health. Taking a new direction requires intensive and sustained public education to support political effort to make the necessary changes.

Population-based data have been useful in Manitoba in persuading politicians and rural community leaders that expanding their hospital's surgical capacity is not necessarily in their constituents' best interests. Because the data suggest similarity in health status across at least some regions, the discussion moves quickly to "how do we ensure that rural residents have access to appropriate (not more) care" (Roos, 1995). Population-based data on needs, health status, and use patterns has been useful in that having key indicators across 54 physician service areas of the province has identified "hot spots," or areas whose population has poor health status, high needs, and average to below average physician supply.

In developing POPULIS, there were and still seem to be a number of barriers to overcome:

a) policymakers often have difficulty changing direction;

b) the determinants of health are influenced by policies of government departments other than health - interdepartmental planning could be a positive outcome from the available results; and

c) at least 15 person-years of principal investigator and programming time were required to develop the original sections of the system - not all provinces/organizations will have the resources to devote to such an undertaking.

One major implication of the analyses from POPULIS is that the province of Manitoba is possibly delivering more health care than is necessary to ensure the health of the population. How then will it be possible to spend less on health care without threatening the health (or the perception of health) of the population? The risks of delivering too much health care are not only financial (Franks et al, 1992). The importance of challenging our assumptions about the relationship between health care and health is also seen in Young's (1988) review of the failure of major targeted expenditures in health care since the 1970s to substantially improve the health of Canada's aboriginal population (Young, 1988). The analyses in the article by Black et al echo this dilemma (Black et al, 1995).

A population-based approach such as this does not dismiss the contribution of medical care. Rather, it represents an attempt to identify the relative strengths of differing contributions - including that of medical care - to the health of the population.

Model B – WHO Strategy of Health for All by the Year 2000:

The World Health Organization (WHO) Strategy of Health for All by the Year 2000 provided the framework for a Health Promotion strategy, used in the Mersey Health Region in the United Kingdom (UK). *Health in the Mersey - A Review* provided a community diagnosis that brought together data from different sectors, compared the health of the Mersey residents with that of the populations of England and Wales and made within-region comparisons between residents of the 10 Mersey health districts (Ashton, 1988). The production of this report was an attempt both to set an agenda for health promotion in the region and to make public information easily accessible to the public.

The process of producing the community diagnosis for Mersey revealed the shortcomings of the available data-base and information systems for Health Promotion. In particular it was clear that much routinely collected data of relevance to Health Promotion was currently not being utilized because it was collected by non-health agencies. In addition

the lack of useful local, as opposed to regional or national data, especially in relation to lifestyles and risk factors, highlighted the necessity for new initiatives.

A short-term working group was convened to examine the information needs for health promotion in relation to regional priorities.

Five categories of data for health promotion were identified:

a) Health Service Data - data which is readily available and merely needs to be organized and presented in a useful way.

b) Related Organization Data - Data covering a wide range of organizations, which is often readily available once arrangements have been made for it to be supplied.

c) Special Survey Data - This forms a significant part of the data needed for Health Promotion and is likely to be the most costly. Typically it is needed to describe the local environments which shape health choices. It seems the need for such data became repeatedly apparent during the production of the Health in the Mersey Report. It is needed to supplement currently available routine statistics and enable monitoring of the achievement of the health goals to take place.

d) Analytically Derived Data - Typically this was related to small area statistics for economic and social variables. Fundamental data are often available (Census based or from National Surveys) but it often needs to be analyzed in relation to a specific topic or at a specific level of disaggregation.

e) 'Soft' Descriptive Data - A complete understanding of each priority topic at a community level requires qualitative data deploying the rich perspectives of anthropology, social and behavioral science.

From a review of health within the Region and of Health strategies in other countries, twelve priority topics for health promotion in the Mersey emerged, based on a consideration of what could be achieved at each point in the human life cycle.

A number of specific indicators were then identified in relation to priority topics and targets were chosen based on their relevance to the priorities and the readiness or availability of supportive indicator data. Underpinning all priorities is the necessity to reorient medical care towards health promotion and primary health care:

a) to develop appropriate education, training and research support for health promotion through collaboration of whichever educational and research establishments are most appropriate;
b) to make appropriate management and planning arrangements based on appropriate health information systems, to ensure the effective and efficient deployment of scarce resources; and
c) to develop local, national and international policies which support health promotion based on public participation and intersectoral collaboration at the local level.

Model C – CATCH (Comprehensive Assessment for Tracking Community Health): A systematic method for assessing the health status of communities has been under development at the University of South Florida since 1991. The system, known as CATCH (Comprehensive Assessment for Tracking Community Health), draws 226 indicators from multiple sources and uses an innovative comparative framework and weighted evaluation criteria to produce a rank-ordered community problem list. The CATCH results from 11 Floridian counties have focused attention on high priority health problems and provided a framework for measuring the impact of health expenditures on community health status outcomes (Studnicki, 1997).

The origin of the CATCH method occurred in 1991 with three grants from the Centers for Disease Control and Prevention (CDC) and the Association of Schools of Public Health (ASPH). While these projects focused on the performance of local health departments, the need to formulate a uniform method of measuring the health status and health needs of communities was reinforced (Studnicki et al, 1994). In a number of

Florida counties, an original household survey was carried out to complement the community profile derived from the secondary data elements composing CATCH. Over time, there were various enhancements to the original method, including revisions and additions to the list of health status indicators and indicator categories; refinement of the peer group selection criteria and process; development of a formal scoring system for rank ordering indicators; and improvements in the design of the various outputs.

CATCH has the following important characteristics:

a) *Multidimensional and Comprehensive* - There are currently 226 indicators organized into 10 categories: demographic characteristics; socioeconomic characteristics; maternal and child health indicators; infectious disease indicators; physical/ environmental health indicators; health status (morbidity and mortality); social and mental health indicators; sentinel events; health resource availability indicators; and behavioral risk factors. These indicators are drawn from multiple sources. For inclusion, each must be uniformly collected, available at the community level, and reside in an existing public database. The indicators used in the CATCH method have been derived from multiple sources and also incorporate many used in assessment instruments developed by other agencies.

b) *Comparative* - For each indicator, the value of the subject county is compared against the mean value of a group of peer counties and the overall state average.

c) *Community Consensus Development* - All indicators for which the subject county value is unfavorable relative to (i.e. worse than) both the peer group value and the state average are then subjected to further analysis. Five additional criteria are applied at this stage to further rank order those indicators that have emerged from the preliminary comparative screening in an unfavorable position relative to both peer group and state average values. These criteria are as follows:

i) number affected;

ii) economic impact;

iii) availability of an efficacious intervention;

iv) magnitude of the difference;

v) trend direction

d) *Weighting of Criteria and Scoring of Indicators* – By using Delphi techniques, consensus on the relative importance and weighting of the individual criteria is achieved by the community advisory group, and if required, expert specialty panels.

e) *Simplified Method Output* – The final output of CATCH, at the community level, is a rank ordering of indicators that represent a profile of the communities' most serious and challenging health status problems. The comprehensive nature of the indicators and the systematic and disciplined way in which each is screened, weighted and scored, enhances the validity of the method as a means of prioritizing health problems.

The current use of CATCH for community health assessments has proven to be an invaluable resource in the Florida communities where it has been implemented (Studnicki et al, 1997). The process has focused attention on high priority health problems and stimulated the establishment of program activities aimed at ameliorating these problems. CATCH has provided the framework for measuring the impact of health expenditures on community health status outcomes. CATCH seems to have served as a catalyst to and coordinating agent for multi-sector involvement of a broad spectrum of community health and health related organizations.

The ultimate potential of the existing CATCH system is constrained by:

i) the current process is labor intensive and slow;

ii) longitudinal trend analyses over many years may be cost prohibitive for many countries;

iii) a state level report format has not been developed because the original objective of CATCH was to assess health status of local communities.

There are plans to automate the CATCH method and to build the infrastructure for new types of analyses. The time required to produce a CATCH report can be reduced with a computer-based data warehouse and automated analysis tools (Kimball, 1996).

Model D – Conceptual Framework (Turnock and Handler):

Turnock and Handler of the School of Public Health at the University of Illinois in Chicago do not offer an example of a successful project or system as such, rather they offer a conceptual framework that views service as an output of the community health system's functions (Turnock and Handler, 1997) - performance monitoring. This proposed framework emerges with several common themes:

i) measurement for the sake of measurement has never been the purpose of these activities;

ii) the intent has consistently been to gather information that would be useful for the improvement of local community health practice;

iii) earlier instruments placed considerable emphasis on results, although generally the results of specific services rather than broader functions - they examined whether things were being done right rather than measuring whether the right things were being done; and

iv) it has been easier to measure aspects of the community health system than to develop consensus as to what these measurements tell us about the effectiveness of community health practice.

The United States (US) Institute of Medicine (IOM) of the National Academy of Sciences, in its report on the Future of Public Health, emphasized that assessment was one of the core functions of community health and recommended that there should be a regular and systematic collection, assemblage, and analysis of information on the health status and needs of communities (Institute of Medicine, 1988).

More recently, the IOM Committee on Using Performance Monitoring to Improve Community Health outlined a Community Health Improvement Process (CHIP) *through which communities can assess health needs and priorities, formulate a health improvement strategy, and use performance indicators as part of a continuing and accountable process*. It was stated that a fundamental requirement for a successful CHIP is the community health profile made up of socio-demographic characteristics, health status and quality of life indicators, health risk factors, health resource indicators, and other measures that can be used in priority setting, resource allocation decisions, and the evaluation of the impact of health programs.

The history of measuring community health practice in the US before the IOM report lacked a conceptual framework. As needs and conditions changed, appropriate community health responses in the form of services changed. Turnock and Handler take the position that an initial set of six basic services (i.e. communicable disease, environmental sanitation, public health lab services, maternal and child health, health education and vital statistics) may have represented an appropriate product of a functioning community health system in the past. But, to measure various aspects of those services as a means of assessing performance of the underlying functions is incomplete at best. Performance measurement in the community health system must be able to measure inputs, processes, outputs, and outcomes in ways that allow for changes in one to be linked with changes in another. The authors suggest a performance measuring system whereby community health organizations are required to be less concerned with the counting of tasks (please refer to **Table 2.4.D** below for an example of past and present performance measures), but rather more concerned with programs and services that are aimed at assessing, developing, managing, investigating, advocating, implementing, and evaluating and most importantly, consulting with and informing the public.

Table 2.4.D:
Comparison of community health practice performance measures past and present (Turnock and Handler, 1997):

Examples of performance measures pre 1995:	**Consolidated panel of core-function related performance measures used today:**
Hospital beds: percentage in approved hospitals.	Assessment: For the jurisdiction served by your local health department, is there a community needs assessment that systematically describes the prevailing health status in the community?
Practicing physicians: population per physician. Practicing dentists: population per dentist. Water: percentage of population in communities over 2500 served with approved sewage systems.	
	In the past three years in your jurisdiction has the local community health agency surveyed the population for behavioral risk factors?

Model E – Healthy People 2000:

The United States (US) Department of Health and Human Services, through its Public Health Service, established a framework for the development of an explicit prevention program for that country. The Year 2000 Health Objectives Planning Act provides legislative support for such a program. To address the requirements of that act and Objective 22.1 of Healthy People 2000, a consensus set of 18 health status indicators have been developed to assist communities in assessing their general health status and in focusing local, state and national efforts in tracking the year 2000 objectives (please see **Table 2.4.E1**). Priority in selecting the indicators was given to measures for which data are readily available and that are commonly used in community health (Morbidity and Mortality Weekly Report, July 1991).

Table 2.4.E1:

Consensus set of indicators for assessing community health status and monitoring progress toward the Year 2000 objectives – United States (US) July 1991

Indicators of health status outcome

1. Race/ ethnicity-specific infant mortality, as measured by the rate (per 1000 live births) of deaths among infants < 1 year of age

Death rates (per 100,000 population – age adjusted to the 1940 standard population)

2. Motor vehicle crashes
3. Work-related injury
4. Suicide
5. Lung cancer
6. Breast cancer
7. Cardiovascular disease
8. Homicide
9. All causes

Reported incidence (per 100,000 population) of:

10. Acquired immunodeficiency syndrome
11. Measles
12. Tuberculosis
13. Primary and secondary syphilis

Indicators of risk factors

14. Incidence of low birth weight, as measured by percentage of total number of live-born infants weighing < 2500 grams at birth
15. Births to adolescents (females aged 10-17 years) as a percentage of total live births
16. Prenatal care, as measured by percentage of mothers delivering live infants who did not receive prenatal care during the first trimester
17. Childhood poverty, as measured by the proportion of children < 15 years of age living in families at or below the poverty level
18. Proportion of persons living in counties exceeding U.S. Environmental Protection Agency standards for air quality during the previous year

The set of health status indicators was developed by a committee established to implement Objective 22.1 through a consensus process involving local, state and federal health officials and representatives from academic institutions and professional associations. The health status indicators were intended to ensure data comparability and facilitate use by community health agencies. These indicators were not intended to

supersede specific measures suggested in Healthy People 2000; however, they were intended to provide a broad indication of the general health status of the community.

In addition to this consensus set of health status indicators, modifications to existing data collection systems have been recommended (see **Table 2.4.E2**) to emphasize additional measures of outcomes, risk factors and processes that will be helpful for planning prevention programs devoted to achieving the year 2000 objectives.

Table 2.4.E2: Priority data needs to augment the consensus set of health status indicators
(Note: The measures in the following areas either did not exist or were incomplete. The CDC Committee identified them as measures that could be obtained with minor modifications to existing data-collection systems.)

Indicators of processes
- Proportion of children under 2 years of age who have been immunized with the basic series (as defined by the Immunization Practices Advisory Committee)
- Proportion of adults aged ≥ 65 years who have been immunized for pneumococcal pneumonia and influenza
- Proportion of assessed rivers, lakes, and estuaries that support beneficial uses (fishing and swimming approved)
- Proportion of women receiving a Papanicolaou smear at an interval appropriate for their age
- Proportion of women receiving a mammogram at an interval appropriate for their age
- Proportion of the population uninsured for medical care
- Proportion of the population without a regular source of primary care (including dental care)

Indicators of risk factors (age-specific prevalence rates)
- Cigarette smoking
- Alcohol misuse
- Obesity
- Hypertension
- Hypercholesterolemia
- Confirmed abuse and neglect of children

Indicators of health status outcomes

- Percentage of children < 5 years of age who are tested and have blood lead levels exceeding 15ug/dL
- Incidence of hepatitis B, per 100,000 population
- Proportion of children aged 6-8 and 15 years with one or more decayed primary or permanent teeth

Model F- Conceptual Framework (Hancock, Labonte and Edwards):

Hancock, Labonte and Edwards prepared a report for the Knowledge Development Division of Health Canada in 1999. In this report the authors outline a conceptual framework for indicator categories, propose criteria for indicator selection and suggest an initial set of core indicators. This indicator set reflects not simply health status, but also the environmental, social and economic determinants of health and the *healthfulness* of the community itself. The authors conclude that if the information in the data set is to be transformed into knowledge that can empower and emancipate the community, it has to be developed in consultation with the community and local users of the information.

Hancock et al. state that the key elements of an assessment of population health at the community level include:

- the aggregate of individual death, disease, disability, behavioral and positive health status (population health outputs)
- the pattern of distribution of such status across the community – inequalities in death, disease, disability and behavioral and positive health status (inequalities of outcomes)
- key indicators of environmental, social and economic determinants of health (population health inputs)
- the distribution of such determinants across the community – inequalities in access to the determinants of health (inequalities of opportunity)
- the healthfulness of the community's processes of governance (participation, social cohesion, civic-ness, etc.) – inequitable distribution of power, participation, etc.

The key conceptual issue in indicator development for the authors is the framework that is used to organize the components. They propose that all models are wrong, in that they present a necessarily simplified version of reality. Nevertheless, the models also represent a perspective on reality that discloses the values and concepts of those who propose them.

The basic framework chosen by the authors is one that has been developed and tested over a number of years (Hancock, 1993); has proven itself to be empirically useful and conceptually strong, and been used in official reports (e.g. Royal Commission on the Future of the Toronto Waterfront, 1992) and by a number of other authors. The basic framework links what have been described as the elements of the three-legged stool of community sustainability and well-being (community, environment and economy) while also paying attention to the links between these three spheres. It also focuses attention on the desired outcome, health.

However, the model as originally developed does not adequately represent several important dimensions of community health and well-being. Specifically, education – a key driver of human development – was not in the model. Accordingly the authors have added another dimension to the model, which they refer to as *processes of change*. The two key drivers of this process are education and governance, which in turn encompasses communication, participation, empowerment, civil rights and government performance. These elements, when in place and working well, are said to independently enhance human health, as well as increase the likelihood that individual, community and political decisions in the three spheres, and their links, will result in the outcome of improved health.

The indicator categories that emerge from this model are congruent with the categories used in a wide variety of community indicator projects that are focused on health status, healthy communities, 'state of the environment reporting,' community sustainability and quality of life issues.

Hancock et al suggest ten categories of indicators arranged in three sets, as follows:

a) The six key determinants (inputs)
   - environmental quality/ ecosystem health
   - economic activity
   - social cohesion/ civic-ness
   - equity (including power)
   - sustainability
   - livability

b) The process by which all this is achieved
   - education
   - participation, empowerment and civil rights
   - government performance

c) The outcome – health status.

Each of these ten categories in turn has a number of subcategories, yielding a total of 58 indicator sub-categories. From these sub-categories, a core set of indicators is suggested [a set of indicators broadly consistent with and reflective of other proposed community-level indicator sets (CMHC/ Environment Canada, 1997)].

Hancock and colleagues have outlined a number of excellent criteria for indicator selection, which includes:

a) local involvement in the selection of the indicators
b) use of multi-stakeholder processes in their development;
c) ease of audience participation
d) measurement of conditions that are significant, comparable and amenable to direct citizen or indirect policy change;
e) disaggregatable down to at least the geopolitically defined community level and broadly representative of the area or condition.

Hancock et al. operate from the principle that indicators are only useful if the process of developing and using them engages the community as a whole in examining what it wants to be, where it wants to go and what its values are; if the process provides useful and usable information to the community; and in the process increases the community's knowledge and power.

Model G – Canadian Institute for Health Information (CIHI):

In response to feedback from a consultation process on health information needs, the Canadian Institute for Health Information (CIHI) launched a collaborative project on health indicators. The purpose of the project was to identify what measures should be used to report on the health of Canadians, the health system and then to compile and make this information widely available.

In May of 1999, the Federal Minister of Health's Advisory Council on Health Info-Structure, CIHI and Statistics Canada brought together health administrators, researchers, caregivers, government officials, health advocacy groups and consumers to identify health information needs. One of the priorities they identified was compiling comparable quality data on key indicators for health and health services, particularly at regional and community level.

The Health Indicator Project was designed to complement and build on initiatives that are already underway or under development at the national, provincial and territorial level. The first step in working towards a common core set of health indicators was to conduct an environmental scan to identify and review related initiatives and to assess the feasibility of possible indicators given the availability and comparability of data from national sources. An iterative modified Delphi process involving stakeholder experts was then undertaken to develop a draft set of health and health care indicators that reflect:

- The overall health of the population served, how it compares to other regions in the province and country and how it is changing over time;

- The major non-medical determinants of health within the region;
- The health services received by the region's residents; and
- The characteristics of the community or the health system that provide useful contextual information.

These indicators formed the basis of deliberations at the first *National Consensus Conference on Population Health Indicators*. Participants at the conference primarily addressed the selection of an initial core set of indicators to populate the framework that can be compiled from current data sources in at least several jurisdictions. Participants first voted on the draft set of indicators derived from the environmental scan.

Indicators where the average of votes was 7.5/10 or higher were automatically retained; those with a score of less than 7 were rejected. Indicators with scores between 7 and 7.5 were reviewed based on voting patterns and discussion at the conference. Based on feedback, the placement of some indicators in the framework was altered, definitions were changed, or indicators were placed on the list for potential future development. Indicators where a resolution was not determined at the conference were rejected if there was substantial variation in participants' votes (standard deviation greater than 2).

The core set of health indicators confirmed at the Consensus Conference was divided into four domains and sub-domains (with a total of 79 indicators proposed within these sub-domains), those being:

- **Health Status**
  - Deaths
  - Health conditions
  - Human Function
  - Well-being
- **Non-Medical Determinants of Health**
  - Health behaviors
  - Living and working conditions
  - Personal resources
  - Environmental factors
- **Health System Performance**

- Acceptability
- Accessibility
- Appropriateness
- Competence
- Continuity
- Effectiveness
- Efficiency
- Safety

- **Community and Health System Characteristics**

While the focus of the Consensus Conference was on indicators that could be compiled from current, comparable data sources, several indicators were also proposed for potential future development. As the Health Indicators Project continues, the list will be expanded and refined.

Compilation, verification, and reporting of comparative data are now beginning for the indicators confirmed at the Consensus Conference. The plan is to use data that are currently available to pilot the indicators at a regional level to ensure relevancy and validity. Over time, the initial indicators will be refined and expanded. The scope and utility of the core set of indicators will also increase as new data are developed, benchmarks are established and knowledge grows. Potential areas for future development include expanded data on personal risk factors, early childhood development, waitlists, drug utilization, home care and health expenditures. These domain-specific projects will contribute to filling many of the current gaps in the indicator framework based on consultations with key stakeholders.

2.5 **Chapter Summary**

Ultimately, as stated by Roos, it is the health of our population that is the fundamental objective for health expenditures. Other outcome measures, such as clinical efficacy and system efficiency, should be seen as building blocks for creating a cost-effective health care sector that improves the health status of communities. **Measurement is a prerequisite of good science.** An effective method to operationalize the concept of community health status is therefore fundamental to the evolution of the science of

community health. Knowledge of correlates and predictors of variation in health status will enhance our ability to identify health priorities, to evaluate program and organizational performance on the basis of their ability to improve health status, and to allocate our scarce resources to the areas of greatest need and with the highest likelihood of positive impact (Roos, 1995).

This chapter has sought to define key concepts dealt with in this thesis. As well, subjective health status measures have been considered. Further, eight (8) population health models and their indicator sets have been examined. There are clearly a number of models to choose from when seeking to measure the health of the population of concern, all with varying degrees of suitability to the population of concern. This project will appraise each model using selected review criteria.

CHAPTER THREE: A Conceptual and Analytical Framework

3.0 Introduction

A review of the concepts of measurement, measurement tools (such as data scaling), health status indicator and population health model selection criteria is presented in this chapter. The resulting conceptual framework was developed to investigate the data source inventory and its utility. This conceptual foundation provides a basis to the selection of health status indicators, health status models, and the rating of information sources.

3.1 Health Status Measurement

Consideration of the measurement of health status begins with two broad purposes. It is, first of all, analytic: specifically, to compare the health status of one individual or group with that of another; or to compare the health status of an individual or group at some time with that at another time. Such analysis, coupled with observations of possible factors affecting health status, can lead to the derivation and judgment of hypotheses as to what influences health (Breslow, 1989).

A second purpose of health measurement is to evaluate deliberate attempts to sustain or improve health, for example, through medical care, health service programming, environmental measures, or behavioral efforts (Breslow, 1989).

3.1.1 Why Measure Health Status?

When searching for measures of health status, one first needs a clear understanding of the reasons for studying health status. The literature suggests (Ware, Brook & Davies, 1981; Bergner, 1987) that these reasons fall into five broad categories:

1. *Measuring the efficiency or effectiveness of medical interventions.*
2. *Assessing quality of care.*

3. *Estimating the needs of a population.*
4. *Improving clinical decisions.*
5. *Understanding the causes and consequences of differences in health.*

3.1.2 **What Aspects of Health are of Interest?**

The literature suggests that a second requirement when selecting health status measures is a clear statement of the aspect of health being studied: specifically, what question about health status is to be addressed (Bodart & Sapirie, 1998)? This requirement addresses both the scope and definition of health status measures (Ware, Brook & Davies, 1981). The proposed project will seek to develop a set of indicators to describe the health status of a particular population, living in a defined geographical location and thus will view health from a group or population perspective.

3.1.3 **How Suitable are the Measures?**

Another important issue to keep in mind when choosing health status measures is their relationship to the underlying expressions of health or disease that is to be measured. Health status cannot be observed directly. One can only make inferences about health from fallible indicators. Having defined the aspect of health about which one wants to know, the next step is to judge the suitability of the available measures (Ware, Brook & Davies, 1981; Bergner, 1987).

A. **Practicality**

A logical first step in the process is a review or inventory of the total measurement resources available and a determination as to how much is useful to inform the health status indicators. The next step is the establishment of priorities for allocating those resources to various health status concepts. Practical considerations will determine

whether any given health status indicator can be considered (Ware, Brook & Davies, 1981). For example, if health is one of the many aspects that needs to be measured, the amount of money and time devoted to health status is obviously limited. Relevant queries as to data collection methods might focus on the possibility of utilizing data already collected for other purposes or the administration of questionnaires to various stakeholders on an ongoing basis (Roos, 1995). Considerations of either of these methods will of course be limited by funding and availability of staff with time for the undertakings.

An important aspect of practicality is respondent burden, indicators of which include refusal rates, rates of missing responses, and administration time (Veit and Ware, 1979).

Finally, when developing and using health status measures, it would seem that working with the least complicated instruments and methods would be most advantageous. At every step along the way – the task presented to respondents, the difficulties faced at the time of scoring, the complexity of interpretation – the simplest approach should be adopted (Miller, Richards & Christenson, 1995). The introduction of complexity, such as items that require reversals in coding, or that must be standardized or weighted before they are summed, makes it more difficult and sometimes impossible for others to use and understand the same instruments, methods, and results (Ware, Brook & Davies, 1981).

B. **Reliability**

Reliability refers to the degree to which the results obtained by a measurement procedure can be replicated. Lack of reliability may arise from divergences between observers or instruments of measurement or instability of the attribute being measured (Last, 1995).

Ware suggests several rules of thumb for reliability (Ware, Davies-Avery, & Donald, 1978). Usually, poorer reliability can be expected from short scales – a single-item

measure rather than a multi-item measure. This seems to hold true for both objective (behavioral) definitions of health and more subjective ratings. Reliability also tends to be lower for those with less education or lower incomes (Ware, Davies-Avery, & Donald, 1978).

C. **Validity**

The term validity refers to the degree to which a measurement measures what it is supposed to measure (Last, 1995).

Validity focuses on the meaning of information contained in the score on a health status measure. A valid score contains information about health status, not some other variable. More specifically, it contains information about the particular aspect of health status needed for the study and the analysis planned (Ware, Brook & Davies, 1981).

Validity can be studied in several different ways. Some are empirical, such as concurrent, construct, and predictive validity. Non-empirical approaches include face and content validity.

Face validity refers to what an item appears to measure based on its manifest content. Content validity refers to how well a measurement battery covers important parts of the health component(s) to be measured. Although both can be very useful in selecting among health status measures, there seems to be general prejudice against using evidence of face and content validity (Ware, Brook & Davies, 1981). This prejudice is unfortunate for at least two reasons:

a) First, analyses of face and content validity are relatively easy to do. All that is needed is a copy of the instrument and an idea of what you want to know. A

look at the content of items in an interview schedule can tell much about the meaning of the responses to the items.

Examining the content of all health status measures considered will help avoid problems that arise because different measures are often given the same label, and the same variable is often labeled differently. To reject the value of assessing face and content validity is to lose a first line of defense against selecting the wrong health status measure and to fall into the mire of confounded definitions of health status and other variables.

b) Another very practical reason for examining face and content validity is that there is rarely more than this available to use in judging the validity of most health status measures. Without exception, available empirical information about validity (concurrent, construct, and predictive) falls short of what is needed (Brook, 1979).

Most of what is known about "validated" health status measures pertains to how much information they provide about health rather than about other variables, such as attitudes toward medical care or satisfaction with care. To know about health status may seem enough, but it is not. Knowing what component of health the measure reflects is also important (Ware, Brook & Davies, 1981).

The literature includes hundreds of studies on health status measurement, and the number of standardized health status measures is increasing. Although this situation can be viewed as a healthy one, the increasing availability of standardized health measures poses a real danger. A particular measure may be tempting because it has been "validated." A "validated" measure may not be valid for the purpose of a given study, however. The best measure of "X" may be of no value if "Y" is the concept to be measured and would thus be rendered invalid. For this reason, the amount of research that has been done to develop and validate a measure should not dictate choice. Before selection, a researcher should

critically review available measurement research findings to determine whether the measure is valid for the purpose of a particular study (Ware, Brook & Davies, 1981; Bergner 1987).

A number of health status measures have already been developed. None is perfect, and selections must be made carefully, according to the particular needs and resources of the planned study, using some of the guidelines previously suggested. Except in special circumstances, new measures need not be developed (Ware, 1987). Given that the reasons for measuring health status have been identified, the aspects of health to be measured specified, and attention paid to the suitability issues already noted, it was determined that appropriate measures and data gathering methods can be found from among those now available.

3.2 **Data Scaling**

After defining and clarifying the concepts to be used in the analysis, methods for quantifying the instrument must be decided (Summers, 1993). Quantification is achieved by attaching a numeric scale to the items. A scale is a set of numbers or symbols assigned to the instrument items, based on rules, to quantify opinions about the concept of interest (Nunnally, 1978). Items to be quantified by establishing scales are usually reserved for measuring perceived opinions, observations, of psychosocial phenomena, and physiological data are usually analyzed as actual values (Summers, 1993).

3.2.1 **Measurement Theory**

In part, measurement theory defines rules for measuring concepts, indicates that the purpose of scales is to make fine distinctions among opinions, and describes sources of error when measuring phenomena (Nunnally, 1978; Waltz, Strickland and Lenz, 1991; Kerlinger, 1986). One overall goal of measurement is to quantify a concept; however,

what is measured is the perceived rather than the actual characteristic. The measurement of perceptions (such as suitability of data sources) differs from physiological measures, which are actual measures.

When any phenomenon is measured, the observed score consists of the true score plus the error score. Systematic error can be introduced when testing facilities or lack of time affect the responses chosen (Summers, 1993). Random error may be introduced when the concept to be measured has not been adequately defined or when scaling is inadequate to spread the variability of scores (Burns and Grove, 1987). When measuring any concept, error is always present, and the purpose of precision in the instrument development process is to decrease systematic and random error. Thus, the overall goal of precision in measurement is to increase the true score component while decreasing the error score component. Therefore, precision in measurement depends on precision in defining concepts, selecting the appropriate scaling method, adhering to level of measurement rules, and developing strategies to minimize the error score (Summers, 1993).

3.2.2 **Level of Measurement Rules**

Measurement rules were derived from measurement theory and are known as level of measurement (Stevens, 1946). Stevens developed level of measurement categories that classify variables by nominal, ordinal, interval or ratio criteria. Ordinal level variables (those of interest in this project) are used to name variables and allow for rank ordering, i.e., placing perceptions of various types of health care practice in rank order from most to least desirable. Rules for ordinal level measures indicate that these data can be counted and placed in rank order (Summers, 1993).

3.2.3 **The Likert Scale**

Regarding pen-and-pencil instruments, many researchers believe that the Likert Scale consists of precise intervals that are sensitive to measures of psychosocial phenomenon (Likert, 1952). The data to be considered for this project would seem to fit into the ordinal category, in that the researcher will be rating the data sources according to the categories of quality and practicality. These are not precise interval categories, but are rather a rank ordering based on the score within the category. When developing an instrument with a Likert Scale, not only must all statements in the instrument reflect the defining characteristics of the concept, but all the scaling labels to quantify the concept must be identical. Please see **Diagram 3.2.3** below for an example.

1. Job stress may contribute to absenteeism.

1	2	3	4	5
Never	Seldom	Sometimes	Frequently	Always

2. Job stress may be manifested by signs and symptoms of depression.

1	2	3	4	5
Never	Seldom	Sometimes	Frequently	Always

Diagram 3.2.3 – Example of a Likert Scale

Many researchers argue that the Likert Scale is ordinal level because the intervals are not precise intervals (Waltz, Strickland and Lenz, 1991). Last defines the Likert Scale as an ordinal scale of responses to a question or statement, ordered in a hierarchical sequence, such as "strongly agree" through "no opinion" to "strongly disagree." (Last, 1995, p. 98). It is assumed that when the process of instrument development begins with concept analysis and progresses through reliability and validity testing, then it is believed that scaling precision is established (Summers, 1993). Another strength of Likert-type scaling instruments is that they are also considered to be a summative rating scale having a total score that can be assigned to concepts or subjects (Summers, 1993).

In the construction of continuous scales, regardless of the specific approach adopted, there are a number of questions which must be addressed in designing a rating scale to maximize precision and minimize bias.

a) *How many steps should there be?* – The choice of the number of steps on a scale is not primarily an aesthetic one. The loss of reliability for seven and ten categories is quite small. However, the use of five categories reduces the reliability by about 12% and the use of only two categories results in an average reduction of the reliability coefficient of 35%. These results have been confirmed by many studies which suggest that the minimum number of categories used by raters should be in the region of five to seven (Streiner and Norman, 1995). Of course, a common problem of ratings is that raters seldom use the extreme positions on the scale, and this should be taken into account when designing the instrument.

The rating scale used for this project has five steps as recommended.

b) *Is there a minimum number of categories?* –There is good evidence that in a wide variety of tasks people are unable to discriminate much beyond seven levels (Streiner & Norman, 1995). Miller showed, in a classic article entitled "The magic number seven plus or minus two: Some limits on our capacity for processing information" (Miller, 1956), that the limit of short-term memory capacity is of the order of seven 'chunks.' Thus it is reasonable to presume that the upper practical limit of useful intervals on a scale can be set at seven.

There are two caveats to this recommendation (Streiner and Norman, 1995). First, recognizing the common end-aversion bias previously mentioned, where people tend to avoid the two extremes of a scale, there may be some advantage to designing nine levels on the scale. Conversely, when a large number of individual items are designed to be summed to create a scale score

(as was undertaken in this project), it is likely that reducing the number of levels to five or three will not result in significant loss of information.

The rating scale used for this project has seven categories as recommended.

c) *Should all of the points on the scale be labeled, or only the ends?* – Most of the research indicates that there is relatively little difference between scales with adjectives under each box and end-anchored scales (Dixon et al, 1984; Newstead & Arnold, 1989), In fact, subjects seem to be more influenced by the adjectives on the ends than those in the intermediate positions (Frisbie & Brandenburg, 1979). There is some tendency for end-anchored scales to pull responses to the ends, producing greater variability. Similarly, if only every other box is defined, the labeled boxes tend to be endorsed more often than the unlabeled ones.

All points were labeled on the rating scale used for this project.

Each source had been rated using the Likert scale for data quality and practicality. A careful review of the literature and knowledge of the area supported equal weighting of the review criteria. Weighting some of the data sources would seem to have resulted in "double counting."

3.2.4 **Critique of Direct Estimation Methods**

Direct estimation methods such as the Likert Scale are pervasive in research involving subjective judgments. They are relatively easy to design, require little pre-testing in contrast to comparative methods, and are easily understood (Streiner and Norman, 1995). Nevertheless, the ease of design and administration is both an asset and a liability; because the intent of questions framed on a rating scale is often obvious to the rater, bias

in response can result. One bias of rating scales is the *halo effect*; since items are frequently ordered in a single column on a page, it is possible to rapidly rate all items on the basis of a global impression, paying little attention to the individual categories. As well, people rarely commit themselves to the extreme categories on the scale, effectively reducing the precision of the instrument. Finally, it is common in ratings of other people, staff or students, to have a strong positive skew, so that the average individual is rated well above average, again sacrificing precision (Streiner and Norman, 1995).

When rating the database inventory for this project it was important for the researcher to be as objective as possible, especially when evaluating organizational data systems. As these systems were familiar, one could have a tendency to be overly protective or overly critical – an attempt was made to be as objective and unbiased as possible in the rating of the information sources. From the literature, established objective criteria were used, as were standard definitions, and protocols. These standards were consistently applied to the data source inventories.

3.3 **Health Status Indicator Selection**

In routine information systems an indicator may be defined as measuring the status of an important variable and permitting the measurement of changes in it over time. An indicator does not describe a situation in its entirety; it may only suggest what a situation is or give a clue to an unmeasurable phenomenon (Bodart and Sapirie, 1998).

Indicators are quantitative measurements, generally including a numerator and denominator, although some measure only a number of events and therefore have only a numerator. The denominator is most often the size of the population at risk for an event. Indicators that include a denominator are useful for monitoring change over time and for comparing areas (CDC, 2000). At the level of the community or health care center, an indicator may be more meaningful if presented as an event, that is the numerator only, than as a proportion or rate. This is especially true for rare but important events, such as a maternal death.

3.3.1 Classification of Reliable Indicators

The process of selecting indicators can be assisted by asking the following questions (Bodart and Sapirie, 1998).

a) *What subject matter should be covered by the indicators?* – Indicators should be chosen which reflect the region's most important health concerns, their determinants, and the main service responses to the problems.

b) *What are the indicators supposed to measure?* – Defining what an indicator is supposed to measure can be more difficult than one might expect, since the meaning must be unambiguous to all concerned. Does it really measure what is intended – i.e. is it valid?

c) *What is the cost and feasibility of collecting data?* – For some indicators the cost of collecting data would be high and the decision not to do so is easy to make. However, in other cases it is not as easy to decide because the cost has to be weighed against the cost of collecting data. The data required for an indicator should be generated through routine services and should be of value for their management (Bodart and Sapirie, 1998).

d) *What decision or action must be taken on the basis of the indicator?* – In other words, what is the relevance of the indicator? An indicator is useful if decisions based on the measurements taken contribute to improvement in the work of health personnel and consequently in the effectiveness and efficiency of the system. Indicators should not be defined unless they are to be used in connection with taking action.

e) *Does the indicator show changes in the situation?* – This is a question of specificity. For example, the infant mortality rate is not a specific indicator of

the effectiveness of health care because it is influenced by many determinants, among them the socioeconomic conditions of households and the care given by parents.

f) *Is a change shown by the indicator a true change in a situation?* – In other words, what is the sensitivity of the indicator? For instance, one would expect the percentage of infants receiving appropriate vaccinations to be a sensitive indicator, since its value changes readily following immunization campaigns.

g) *Is the indicator ethical?* – It might be considered unethical, for example, to adopt an oral health indicator of decayed, missing and filled teeth based on a survey conducted in an area where no dental services were available. It is necessary to have programs/ services to respond to needs or else use the data as a baseline to lobby to acquire services.

3.3.2 **Making Indicators Operational**

Lippeveld et al suggest that once an indicator has been accepted as appropriate and desirable, it has to be further defined in order to make it operational. This is done by answering the following questions (Lippeveld, Sauerborn and Sapirie, 1997).

a) *What are the sources of the data?* – Where can the required data be found? Who will be responsible for the collection? What method of collection will be used? It is important that the recording and collection of the data at its source serve a need for decision making or action at the same level.

b) *What should be the frequencies of collecting this data and processing and analyzing the indicator?* – The frequency of data collection should be

determined by the urgency of the decision to be made or the speed of change in the measured variable.

c) *Who will use the indicator and how?* – The indicator should first be analyzed and used for decision making by the staff collecting and reporting the data. The specific action to be taken on the basis of the indicator should be confirmed and the decision criteria should be recorded in clinical or managerial procedures.

d) *What is the relation between an indicator and the target?* – It is common practice to set targets because the gap between measurement and objective helps decision making. Thus targets are normally set in districts for number of children in a new cohort aged under one year which must be fully immunized within a year. However, not all targets can be expressed as indicators.

e) *What is the threshold of the indicator which should trigger action?* – The determination of a threshold for an indicator can help decision making. Health staff should determine thresholds in accordance with standards or local needs and resources.

f) *What is the nature of the action or decision once the indicator reaches its threshold value?* – Clearly, action is necessary if benefit is to be derived from the indicator.

This thesis concentrated on answering the first of these questions posed by Lippeveld et al. The remainder of the queries are well beyond the scope of this undertaking.

3.4 **Choosing the Health Status Monitoring Model**

Health status indicators are primarily intended to support health authorities in monitoring progress in improving health, maintaining the health of the population and the functioning of the health system for which they are responsible. In addition, the indicators should assist with reporting to governing bodies, the public, and health professional groups (National Consensus Conference on Population Health Indicators, 1999).

The criteria used for identifying key indicators, and hence a population health model, were based on the regional organization's evaluatory needs to monitor mandatory programs and organizational performance and are as follows:

a) The model should be built by consensus.
b) There should be a close match to the required organizational indicators (please see **Appendix A**) and that of the model (please see **Appendix B**).
c) The indicators within the model should be generally available in the region through currently available data sources.
d) The model should be readily adaptable.
e) There should be resources available to adapt the model for use in the region in a timely fashion.

These same criteria were also confirmed by the work of the Health Data Technical Working Group (Health Canada, 1999), which was seeking to identify health indicators for their aboriginal clients.

The health care organization of concern will be able to supplement a core set of indicators with locally collected or special purpose data focusing on the health priorities within the geographic locale such as, language retention rate, birth rate, disability rate, general mortality rate, transportation to care rate, and so on.

3.5 A Framework for Data Source Analysis

Data collected for other purposes may not be sufficient for health status monitoring needs. Limitations of such data may include lack of timeliness of data collection or data availability, incomplete data, non-representatives of the population, problems with data quality and limited time frame of data (i.e., data that have only been collected for a short period of time) (Goldman et al, 1992; Holzner et al, 1993; Thacker et al, 1996; Health Canada, 1999; Centers for Disease Control and Prevention, 2000).

A framework for analysis, an assessment of the quality, utility and accessibility of the data, where data were available, emerged from the literature with the following query criteria consistently arising:

i) are the data available in a timely manner and at a reasonable cost (Goldman et al, 1992; Thacker et al, 1996);
ii) are the data complete (Holzner et al, 1993; Thacker et al, 1996);
iii) are the data representative of the population of interest (Centers for Disease Control and Prevention, 2000; Health Canada, 1999);
iv) are the data of good quality (Holzner et al, 1993; Health Canada, 1999);
v) are the data useful at the regional, provincial or national level only (Health Canada, 1999; Centers for Disease Control and Prevention, 2000);
vi) do the data only cover a limited time frame (Thacker et al, 1996; Centers for Disease Control and Prevention, 2000);
vii) are the data useful or necessary at this time or even needed to inform the chosen indicator set.

The critical factor in this data source review will be utility/ necessity. If the project does not need the information source to inform the indicator set, the source will be eliminated without further consideration. Data sources containing necessary information will then be rated, using a Likert rating scale, according to the above noted criteria. From the literature, these criteria appear to be falling into two logical categories, that of Data Quality and Data Practicality. The rating criteria for Data Quality will include: timeliness,

completeness of data, a support system in place, reliability, ease of usage, flexibility, and acceptability. The rating criteria for Data Practicality will include: accessibility, cost, the degree to which the system is ethical, the availability of denominator information, the presence of a unique identifier, whether the data are formatted, and the presence of data archives.

3.6 **Chapter Summary**

Through a review of the literature presented and an assessment of areas of convergence among the various sources, the researcher has developed a conceptual framework to review and critically appraise the health status monitoring models and data sources available to the region. The components of this framework are:

a) An agreement on the overriding principle that the measurement of health status is useful and necessary;
b) A review of the concepts of measurement, suitability of measures, measurement theory and data scaling;
c) A review of health data sources, and hence health status indicator selection criteria, through an elimination process and subsequent rating system; and
d) The formulation of criteria for choosing a suitable health status monitoring tool for the region of concern.

CHAPTER FOUR: Methods

4.0 Introduction

As the basis for the development of a health status monitoring system for the population of concern, the starting point for the researcher was an inventory of potential health and social indicator data sources available within and outside the region – data sources relevant to the population of interest. This type of inventory falls within the recommendations made by the Federal-Provincial-Territorial (FPT) Surveillance Integration Design Team, in its recent report "An Integrated National Health Surveillance Network for Canada" (Health Canada, 1998). One of its five recommendations included improving access to existing information – "inventories of existing data sources, metadata and expertise, together with a portal or 'single window' means of access, using new technology, particularly to facilitate timely access to data" (Wigle & Mowat, 1999).

This thesis is exploratory in nature and seeks to investigate, review, and describe relevant and available data sources. The project also seeks to utilize components of these data sources where feasible.

4.1 Ethical Approval

Prior to commencement of data collection, the research project was approved by the supporting agency as an administrative inventory. Because the project would not require direct interaction with the general public, but would rather be reviewing the format of previously collected health information, the project did not require approval at the Health Committee level of the Labrador Inuit Association (LIA) Board or the Human Investigation Committee (HIC) of Memorial University of Newfoundland. The project was seen as an inventory being conducted for/ by the supporting agency.

4.2 Methods

The following steps were taken to achieve project goals.

4.2.1 **Literature Review and Choice of Health Status Monitoring Model**

A review was undertaken (previously described in **Chapter Two**) to review the models of health status measurement available throughout the community health literature. A model was chosen based on the following review criteria and further substantiated in the conceptual and analytical framework (**Chapter Three**):

a) The model should be built by consensus.
b) There should be a close match to the required organizational indicators.
c) The indicators within this model should be generally available in the region through currently available data sources.
d) The model should be readily adaptable.
e) There should be resources available to adapt this model for use in the region in a timely fashion.

4.2.2 **Data Sources Inventory**

An inventory of health and social indicator data sources, relevant to the population of concern, was compiled through key informant discussions/ interactions with various stakeholders within and outside the region.

A. **Key Informant Interviews**

A letter of invitation was sent to each agency outlining the reason for the inventory and its possible benefit to our mutual clientele (please refer to **Appendix E**). The invitation letter to potential respondent agencies introduced the concept of health status monitoring and the postulated need to develop a comprehensive system for monitoring the health of our mutual clients over time. This correspondence also requested a general outline, where possible, of data collected by the agency, its format (i.e. hard or electronic copy) and final usage. Individual information was not requested from the database, rather an interest was expressed in the scope, depth and accessibility of the tool rather than information about individuals – the researcher was interested in a population approach rather than an individual approach.

This correspondence was sent to stakeholders in November and December of 1998. Follow-up telephone calls were undertaken, with three (3) unreturned calls being used to represent a non-response.

Key query concepts had previously been identified through communication and confirmation with the Labrador Inuit Health Commission (LIHC) Research Co-ordination Group. Semi-structured, key informant interviews (Patton, 1980; Bordens and Abbot, 1991; Creswell, 1994) were conducted, with queries on the following concepts:

a) Information source of the data
b) Specific fields contained within the database
c) Present end use of the data
d) Data input and update capability
e) Data system/ platform (i.e. hard copy, electronic, etc.)
f) Accessibility or shareability of the data.

These interviews were carried out with individuals from identified organizations and groups. Prior to the commencement of the interviews, the outline, purpose and intent of the study was explained to each agency representative. These interviews took place by telephone or in person, and were from one-half hour to one hour in duration. All interviews were conducted in the English language.

Following the completion of each interview, notes and responses were reviewed, transcribed and put into a consistent format to facilitate eventual comparison and determination of data component availability. Information gathered was stored in a locked file in the researcher's office. This file is only accessible to the researcher. The results of the inventory were organized consistently and systematically by agency listing.

Table 4.2.2.A **Listing of Key Informant Groupings and Agencies**

Grouping	**Type of Agency or Data Source**
Labrador Inuit Data Sources	Health
	Post Secondary Student Support Program
	Membership
	Social Programs
	Employment Support Services
	Housing
	LIA Training and Education Database
	Economic Development
Provincial Health Care	Health and Community Services
	Communicable Disease Control (CDC)
	Addictions Services
	Provincial Perinatal Committee
	Administrative System
Hospital Services	Health Labrador Corporation (HLC)
Registries	Cancer Registry
	Tuberculosis Registry
Health Administration	Medical Care Commission (MCP)
Legal Services	Labrador Legal Services
	Provincial Department of Justice
Policing	Royal Canadian Mounted Police (RCMP)
Church	Moravian Church in Labrador
Educational System	Labrador School Board
	Labrador Institute (MUN)
	Provincial Department of Education
Health/ Social Information	Newfoundland and Labrador Center for Health Information (NLCHI)
	Canadian Institute for Health Information (CIHI)
Special Surveys	Aboriginal Peoples Survey (APS), Statistics Canada
	Labrador Inuit Regional Health Survey (1997)
Municipal Government	Municipal Councils
Vital Statistics	Provincial Department of Government Services and Lands
Federal Health	Community Workload Increase System (CWIS)
	Health Information System (HIS)

Data were collected within an approximate one-year time frame, i.e. from November 1998 to December 1999.

4.2.3 First Stage Elimination Process – Data Source Review

Formulation of the data source inventory yielded a great deal of potential information that could be utilized to inform the selected health status monitoring tool. From this listing, an initial categorization was carried out which identified data sources with like and unlike data. Data limitations and challenges were emerging from this initial organization.

The next step in the process was to decide which data sources were needed or even useful to the monitoring tool. Inventory analysis, an assessment of the quality, utility and accessibility of the data, where data were available, was undertaken with the following factors being utilized to review the information:

a) are the data available in a timely manner and at a reasonable cost;
b) are the data complete;
c) are the data representative of the population of interest
d) are the data useful at the regional, provincial or national level;
e) are the data of good quality;
f) do the data only cover a limited time frame;
g) are the data useful or necessary at this time or even needed to inform the chosen indicator set

The critical factor in this review was utility/ necessity. If the project did not need the information source to inform the indicator set, the source was eliminated without further consideration. Data sources containing like-information were then rated as to the above criteria.

This inventory analysis resulted in the elimination of a number of data sources which were unable to meet the first criteria level.

The data inventory was organized and analyzed manually by the researcher.

4.2.4 **Second Stage Elimination Process - Data Scaling**

A scaling method was then formulated to review the remaining data sources to rate those that were most suitable based on the chosen criteria of practicality and data quality.

a) Step One - a review of each database as to **Data Quality**, based on a data category scaling method utilizing the Likert (Likert, 1952) rating scale for continuous ordinal data; a scale which contained five steps and seven rating levels;
b) Step Two – a review of each database as to **Data Practicality**, again using a Likert rating scale with five steps and seven rating levels;
c) Step Three - following this rating (because the Likert Scale allows the scores in each category to receive a summative rating with the assigning of a total score [Summers, 1993]) it was expected that the inventories with the highest ratings would be utilized to inform the health status monitoring tool. A final set of data sources was chosen from information currently available to the region.

4.2.5 **Identification of Informational Limitations**

Informational limitations were uncovered and outlined. Suggestions were made as to how these limitations can be overcome.

4.2.6 **The Health Status Measurement Tool for the Region**

The Health Status Measurement Tool and the available sources of data were matched (see **Appendix C**). While building upon current resources and offering suggestions to meet the challenge of data limitations, a data collection tool was proposed that can be used to facilitate health status measurement for the area of interest.

CHAPTER FIVE: The Data and Information Resource Inventory

5.0 Introduction

This chapter presents the health and social systems data and information sources inventory pertinent to Labrador Inuit collected between November 1998 and December 1999. The chapter opens with a listing of the various data sources by category i.e. aboriginal groups, provincial health care, federal health care, and so on and then moves on to further describe the various data sources in some detail.

Table 5.0 **Key Informant Agencies and their Data Sources by Category**

Type of Agency	Agency Subdivision	Additional Information	Number of in-house data sources
Aboriginal Groups	Health		
	- Non-Insured Health Benefits (NIHB):	Created in the *Alpha 4* platform	1 electronic database
	- Patient Statistics	Created in the *File Maker Pro* platform	1 electronic database
	- Air transportation		1 electronic database
	- Orthotics and prosthetics		1 electronic database
	- Glasses		
	- Ground Transportation		1 electronic database
	- Community Health:		
	- Public Health Birth Books	Hard copy records of births in coastal communities (individual records)	Hard copy only
	- Public Health Death Books	Hard copy records of deaths in coastal communities (individual records)	Hard copy only
	- Community Profiles	Hard copy snapshots of the health of each community within each calendar year.	Hard copy, formatted into *Windows 98*
	- Addictions treatment Center client database	TARS (Treatment Activity Reporting System) client (individual) database	1 electronic database

	- Addictions Center Administrative system		1 electronic database
	- Mental Health - Counseling - Crisis Line - Crisis Response Report - Intentional Injuries - Community Education - Staff Training - In-Service Training	All databases have been created on the *Alpha 4* platform	7 electronic databases – four of which are currently active
	- Labrador Inuit Regional Health Survey	Conducted in 1997, this survey contains a great deal of individual health perception data, which has been analyzed by community and region.	Hard copies of regional and community data exists in binder format. Electronic copies of survey results have been formatted in *Epi Info*.
	Post-secondary student support system (PSSSP)	Created in the *Fox Pro* Platform – can formulate reports on individual students and the PSSSP program in general	1 electronic database
	Membership listing	Created in the *File Maker Pro* database. This is an individual based system.	1 electronic database
	Social Programs		0 databases reported
	Torngait Services (TSI) - Employment Database	Created in *Microsoft Access* and is an individual based system.	1 electronic database useful for TSI business only
	Housing		0 databases reported
	LIA Training and Education Database	Created in *Microsoft Access* and is an individual based system which can answer questions as to numbers within a community or region	1 electronic database
	Economic development		0 databases reported
Provincial health care	Health and Community Services (formerly Social Services): - Young Offenders Information System (YOIS) - Child Welfare Information System - Child Care Population Movement - Group Home Population Movement	Data is collected and reported manually. Data is collected and reported manually. Data is collected and reported manually.	1 electronic database

	Communicable Disease Control (CDC) - Communicable Disease Control Database (provincial)	Can be accessed by CDCNs and provincial PH staff. Formulated on *SQL* system.	1 electronic database
	- Immunization database (provincial)	Created within a system known as *File Magic* (individual).	1 electronic database
	- Immunization database (Melville Hospital)	Created in Microsoft *Fox Pro* (individual).	1 electronic file
	- Regional TB Database	Created *within Alpha 4*, recently converted into *File Maker Pro*	1 electronic database
	Client and Referral Management System (CRMS) will contain: - Child Welfare Registration (CWRS) - Communicable Disease Control (CDC) - Child Health Clinic (CHC) - Workload Management Project (WMP) - Integrated Support Services Program (ISSP) - Wait Lists - Young Offenders Information System (YOIS) - Family Assistance Database (FACTS) - Cervical Screening	This system will facilitate the sharing of client information between care providers with the CH sector and is to some degree in the developmental stages.	9 electronic databases (not all integrated to date, with some replacing other already mentioned systems) The Labrador roll-out on this project has been put on hold to date.
	Community Health Nursing Information System (CHNIS)	Regular regional reporting to provincial department	1 electronic database (not regularly reported to regions)
	Integrated Support Services Program (ISSP)	Profiles of children and youth receiving services	Currently in hard copy only
Hospital Services	Administrative system (Health Labrador Corporation - HLC, Goose Bay) - HLC records of clinic		Hard copy records

	and home visits - HLC records of hospital emergency visits, laboratory and radiology utilization - LOPHID breast-feeding database - makes use of CIHI (inpatient and day surgery utilization data) - makes use of MCP – physician utilization - makes use of NLCHI – regional mortality statistics - makes use of provincial cancer registry - makes use of Statistics Canada data	(Information from CIHI can be used to generate aggregate records of hospital utilization based on patient's place of residence.)	Hard copy records 1 electronic database
	Addictions services (Goose Bay) - Clinical Database Management System (CDMS)	A provincial system	1 electronic database
Newfoundland and Labrador Provincial Perinatal Committee – Janeway Child Health Centre, St. John's	Provincial Perinatal Program	Collection, analysis, interpretation and reporting of perinatal events.	
Department of Employment and Labor Relations	Occupational Health and Safety Division	Work Injuries Database	1 electronic database
Newfoundland Medical Care Commission (MCP)	Administrative system (St. John's)		1 electronic database
Labrador Legal Services (LLS)	- Listing of inmates at the Labrador Correctional Center - Court dockets - Provincial court records	(From 1981-1995)	Hard copy format Hard copy format 1 electronic database
Law Courts, Department of Justice	Provincial Court Information System	Provides client information on case management, fines and offense history.	
Community Corrections, Department of Justice	Community Corrections Information System	Tracks client upon conditional release to the community.	
Adult Corrections, Department of Justice	Sentence Administration Information System	Contains information on the sentence given to persons convicted of a crime.	
Criminal Law Division, Department of Justice	Crown Attorney Case Management System	Criminal investigation data.	

Statistics Canada	Population demographics and projections	Available on the Internet; profiles of provinces can be purchased. Data compiled every 5 years from census (1996 and then again in 2001). Many surveys/ year are conducted by Stats Can. Also has information on i.e. household spending, crime statistics, EI rates, causes of death, and health administrative statistics.	
Federal health care	Community Workload Increase System (CWIS)	A Federal financial management system	1 electronic database
	National Health Surveillance Infostructure (NHSI)	This is the federal component of the Network for Health Surveillance in Canada (NHSC). It currently includes a series of six (6) pilot projects which are listed as follows:	Not a database – a network currently in the developmental stages.
		Canadian Integrated Public Health System (CIPHS)	
		Spatial Public Health INformation eXchange (SPHINX)	
		Product Related Risk Data Network (ProdNet)	
		IM Infrastructure	
		Skills Enhancement for Health Surveillance (SEHS)	
		Addressing Health Surveillance Data Gaps (AHSDG)	
	Health Information System (HIS)	This is the federally developed Health Information System (HIS), which is being used to assist aboriginal groups as they transfer health care services.	A specially developed electronic database with eight (8) systems and five (5) subsystems.
	Canadian Institute for Health Information (CIHI)	A national system housing 15 databases of health related information (i.e. expenditures, health professional numbers, health services databases and registries).	15 electronic databases
Moravian Church	- Baptismal Records	All records are in hard	6 sets of hard copy records

	- Minister's Records - List of Chapel Servants - List of those confirmed and Admitted to Holy Communion - List of Persons Joined in Holy Matrimony - List of those Departed this Life - Ordinations	copy format. All records are Individual social/ health database systems	– some dating back to the 1700's
Cancer Registry	- Tumor Registry - Cytology Registry	Both are Individual health database systems	2 electronic databases
Tuberculosis Registry	This registry is contained within the CDC database	The records are individually based	
Educational system (Labrador School Board)		Information on students is collected on hard copy at the community level and forwarded to Board level annually.	0 – no electronic database reported. *WinSchool* is scheduled to be used in the future.
Provincial Department of Education (Research, Statistics and Planning Division)	High School Transcript Information System. Student Withdrawal Information System.	Includes year end course marks for individual students province wide. Tracks students who have withdrawn from high school prior to graduating.	
Labrador Institute. Memorial University of Newfoundland (MUN)	No databases reported in this topic area		0 databases reported
Newfoundland and Labrador Center for Health Information (NLCHI)	This center utilizes information from the Clinical Database Management System (CDMS), the Canadian Institute for Health Information (CIHI) and other sources to prepare reports for widespread release across the province.		
Municipal Councils	Administrative system	Individual listings for taxation and municipal enumeration purposes.	Hard copy data
Vital Statistics Division (Department of Government Services and Lands)	Registration of vital statistics.	Births, deaths, and marriages.	

5.1 **Reviewing Existing Data Sources**

5.1.1 **Vital Statistics**

Vital Statistics agencies in each Canadian province are legally mandated to register all births, deaths and marriages which occur in the province. Notification of a birth or a death is completed by a nurse and/ or a physician. As a result of the legal mandate, these registries are generally understood to be the most comprehensive source of birth and death information.

Computerized summary records of births, deaths and marriages are created from official notification certificates (i.e. Live Birth Notification Form [LBNF], Birth Certificate, parental application, Marriage Certificate and the Death Certificate). In the case of births, these records report birth date, sex, given names and surname (maternal age, maternal given name and surname) and geographic location (of birth, of maternal residence). Mortality records include date of death, sex, given names and surname, and geographic location. The underlying cause of death is recorded in accordance with the rules and codes of the 9th revision of the International Classification of Diseases (ICD-9).

Currently, Vital Statistics is a division of the provincial Department of Government Services and Lands. Data are available as annual reports, as monthly summaries for health regions, and on special requests (these requests have been funneled through the Newfoundland and Labrador Center for Health Information [NLCHI] since its creation in 1997).

5.1.2 **Hospital and Medical Care Utilization**

Insured health care services in Newfoundland and Labrador include inpatient and outpatient hospital care, physician services, and services provided by mental health care

providers. It is important to note that medical care for the majority of occupational-related injury and disease is insured by the Workplace Health and Safety Board. With the exception of medical care provided under the auspices of the Workplace Health and Safety Board, computerized records of health care encounters are available for all insured services listed above.

A. **Hospital Services Database**

Information available from the Canadian Institute for Health Information (CIHI) can be used to generate reports of all hospital utilization based on patients' place of residence. Features of the reports that would be possible include gender, age group, diagnosis, doctor service, Case Mix Group (CMG), procedure, separations, patient-days and hospital of service. Access to information on other Canadian regions/ populations is also possible for comparison purposes. Much of this information generally measures service utilization.

Such information has limited utility as it reports only on service demand, not need. If case finding and screening are weak, or if access to service is limited, need will obviously be greater than demand/ utilization. As well, the information currently being generated from CIHI (through the NLCHI) about Labrador is in a generic format, in that all groups are lumped together. Therefore, the aboriginal health care provider would not be able to receive information/ reports on the health status of its particular clientele from the current data format. This clumping has been recognized as a limitation by a number of stakeholders and is to be addressed by the Newfoundland and Labrador Center for Health Information (NLCHI).

The Melville Hospital in Goose Bay has also recently developed a breast-feeding database. This electronic database, developed through the Health Canada funded LOPHID (Local Public Health Infrastructure Development) Project, outlines numbers

and duration of breast-feeding clients. Baseline information for this database was formulated from a review of the Live Birth Notification Form (LBNF) for the region, completed when mother and child are discharged from the health care facility. This information was further supplemented by a partial survey of the region. Unfortunately, the northern Labrador region was not surveyed, thus information available to our organization would have been obtained from the LBNF only.

5.1.3 **Medical Care Insurance Database**

The Newfoundland Medical Care Plan (MCP) provides medical insurance to residents of the province for most medical and certain dental services. The Newfoundland Medical Care Commission administers the Medical Care Insurance Act and is responsible for all matters relating to the payment of fee-for-service providers under this act. In 1969, a computerized Registration Master File of beneficiaries was developed at the Commission and residents of the province were issued an MCP number and a plastic card containing their name and number. This system is still in use today.

The current system does not cover in-hospital costs, air ambulance and so on – these services come directly under the provincial Department of Health. In the course of reimbursing physicians, the branch accumulates files on clients and their attending physicians. These files contain information on patient identification (with the MCP number being the personal identifier), the type, date and location of the service, a single three-digit ICD-9 diagnostic code describing the reason for the physician visit, and information on the physician who provided the services.

General registration fields include name, address, telephone number, and information source (i.e. birth certificate or Social Insurance Number) supplied by the applicant. This data and other data included in an individual personal file are linked by the MCP number, a number usually applied for at birth or upon entering the province as a long-term

resident. Data can be added electronically to the MCP system by staff of the service provider, but the system cannot be accessed for information retrieval by these individuals. Data is updated as clients access services of these health care professionals.

NewTel Information Solutions (NIS) is responsible for the development, implementation and operation of computer-based systems for the Commission. The processing of claims is done on a mainframe computer housed at NIS, and a microcomputer-based network is used to receive claims (approximately 97% of physicians submit claims electronically). Payment occurs every two weeks, with reconciliation done electronically. The MCP registry is an IDMS database, also running on the NIS mainframe. A staff of six to seven people maintains the registry. No one else has access to the registry for purposes of checking or updating client demographics.

It is reported that Ministerial data exchange agreements for specific fields – such as home address – between government departments are possible from this database.

5.1.4 **Disease Registries**

Disease registries for certain chronic conditions are important sources of incidence and prevalence data, especially if they are population based.

A. **Cancer Registry**

The Newfoundland Cancer Treatment and Research Foundation manages two electronic databases for its everyday work. When the Foundation came into being in 1971, it inherited the Tumor Registry, begun in 1969. Fields within this registry include name, date of birth, address. MCP number, next of kin, place of birth and maiden name. This registry also contains tumor information obtained from pathology reports and death certificates.

The Cancer Tumor Registry is used:

a) For follow-up on clients who have been diagnosed with a malignant tumor, excluding skin cancer – i.e. follow-up correspondence is generated annually from the system if updates have not been received on individual clients;
b) For provincial or regional statistical purposes i.e. the number of people with lung tumors in the Labrador region or in Labrador Inuit communities. (This type of report can be requested and received within a 3-4 week period.) Information on specific individuals is restricted to physicians, cancer foundations nurses, etc on a need-to-know basis.

The Cytology Registry, begun in 1969, has been more recently computerized, hence is less up to date than the previous registry. There is also a greater volume of information to input as data comes from Papanicolaou (PAP) smear reports, which are collected on a relatively regular basis. This form contains a great deal of personal information, including client name, date of birth, MCP number, etc.

Information in this database is currently used for statistical purposes only, i.e. number of PAP smears done provincially, regionally; number of abnormal smears; age range of individuals receiving smears, etc. Data are entered by data entry staff at the Bliss Murphy Cancer Center, in St. John's, from individual Pap smear forms.

B. **Tuberculosis (TB) Registry**

The Tuberculosis (TB) Registry is housed at the Department of Health, Disease Control and Epidemiology Division, in St. John's. This disease database exists within the Communicable Disease (CD) Reporting system – transmitted weekly by Communicable Disease Control Nurses (CDCN) for each of the six (6) health care regions within the province. All active cases of TB since 1990 (new and old) are held on this electronic database. (Plans are underway to enter cases before that date as soon as possible.)

Information regarding cases of TB is received via a form entitled *Active Tuberculosis Report Form – New and Relapsed Cases*, which is completed by the CDCN for the region of concern. This information usually provides client name, MCP number, date of birth, sex, usual residence, origin (i.e. Inuit, Indian, foreign-born), diagnosis date, diagnosis code (using the ICD –9 system), bacillary status, case criteria, date treatment started, treatment regimen, case finding information, and HIV status. Information on new and old cases can be obtained by Community Health staff from the Communicable Disease Technician as required. (It should be noted that information regarding TB testing, BCG dates, etc. is contained within the Immunization database held at the same Department.)

Since 1997, the Laboratory Center for Disease Control (LCDC) at the Federal level has required the completion of a form entitled *Treatment Outcome of a New or Relapsed Tuberculosis Case* on each new TB case diagnosed. The information from these forms will now have to be incorporated/ designed into the TB Registry to ensure record completeness (yet to be undertaken).

5.1.5 **Communicable Disease Control Database**

The Communicable Disease Control (CDC) program for Newfoundland and Labrador maintains a registry of the reportable communicable diseases within the province. Sources of information include notification by physicians, primary care nurses and reports from laboratories. Regional information is transmitted weekly by Communicable Disease Control Nurses (CDCN) for each of the six (6) health care regions within the province. This system has been developed and tailored to meet provincial CDC needs. Regional CDCNs can transmit information to the St. John's office and can receive incidence and prevalence data pertinent to their region, but cannot receive data about other regions – except in aggregate format. Diseases from List A of *Notifiable Diseases* (September 1998) require immediate reporting in detail, List B requires detailed reporting not necessarily immediate and reporting in List C requires aggregate format only.

Quarterly reports are published for health care providers from the CDC database, outlining communicable disease contraction regionally and provincially, often comparing provincial to national rates. This system provides the ability to perform disease surveillance and contact tracing. It also provides the ability to transmit to a provincial database.

This database also contains a number of registries, those being:

a) HIV/AIDS
b) Syphilis
c) Meningococcal
d) Measles
e) Hepatitis B
f) Hepatitis C

Fields within this database would include name, date of birth, MCP number, sex, age, and so on (information that would come from the PH lab form when being filled in by health care staff at the clinical end of the system).

5.1.6 **Special Surveys and Studies**

A. **Aboriginal Peoples Survey (APS)**

The Aboriginal Peoples Survey (APS), last conducted in 1991, offers the most comprehensive look at health status and health determinants in the aboriginal population of Canada. Microdata from the APS, i.e. unaggregated records of individual responses to the survey, are assembled in a fashion that can be analyzed by individuals who purchase them from Statistics Canada. Three sets of microdata from the APS – the adult, children and housing files – have been released from Statistics Canada to the general public. Statistics Canada has also released "community profiles," which present counts and prevalence of variables by individual community. These profiles are available on the Internet at www.statcan.ca.

B. Labrador Inuit Regional Health Survey (LIRHS)

The 1997 Regional Health Survey provided information on the general health of Labrador Inuit living in the northern coastal communities. Adequate information as to the health status of the population, and the factors associated with good and poor health, had not previously been available. The Labrador Inuit Health Commission (LIHC) is using the results of the survey to plan, develop and evaluate its programs and services. (It should be noted that comparability of the LIRHS and the Aboriginal Peoples Survey (APS) was ensured through review and standardization of the utilized questions.)

Interviews for the Health Survey were carried out in the spring of 1997. Every Labrador Inuit Association (LIA) household in the five coastal communities was asked to participate. The head of the household provided information for the household, for her/himself as an individual, and for one of the children in the household by proxy. The survey participation rate for the region was 85%.

The survey requested respondents to provide information as to age, sex, martial status, education, language, work and income. A series of nine (9) newsletters was developed entitled "What you told us..." to provide the topical results of the survey back to the respondents in a meaningful manner - i.e. appropriate language. Topics included:

a) The Health Survey (how it was done and what it was all about)
b) Women's Health
c) Nutrition/ Diet
d) Your Health
e) Smoking
f) Addictions
g) Mental Health
h) Children's Health
i) Social and Environmental Concerns

The results of this survey exist in hard copy format in each participant community and regionally, where data are also housed in *Microsoft Word* and *Access* format. Discussions

are currently underway to investigate the possibility of conducting the survey longitudinally.

5.1.7 Socio-Economic Data Sources

There are a wide variety of data sources on the use of social services and socioeconomic indicators, with differing degrees of centralization, computerization and ease of retrieval. Those sources which are deemed to be the most relevant to health are reviewed and described.

A. Community Workload Increase System (CWIS)

The Community Workload Increase System (CWIS) project was commissioned by the Federal Department of Health and Welfare Canada, Medical Services Branch (MSB) in 1993 to assess resource requirements to provide basic health services to First Nations and Inuit throughout Canada. The system was developed as a mechanism to justify resource requirements necessary to deliver essential services in First Nations and Inuit communities by Indian and Northern health professionals and paraprofessionals due to workload increases.

The system considers basic levels of health services, the actual numbers of clients for each service multiplied by the established schedules for health service delivery (i.e. World Health Organization, Victorian Order of Nurses).

The formulas are based on the mandatory services being provided by the individual health care workers in the communities (including transferred communities). The formula varies, taking into account factors such as the community's isolation; the basic levels of health services; the actual numbers of clients; the established schedules for health service delivery; and the accessibility of physician services. Program statistics are collected for all communities on a yearly basis and the formula is then calculated and substantiated to

Treasury Board. The CWIS is maintained on a national computerized system and each aspect is monitored at the Branch level (i.e. MSB Atlantic Region).

The CWIS is an ongoing system. Forms are completed annually by the aboriginal health care group. The form consists of three pages, of seventeen (17) items:

a) Page One – Community identification, demographic, population and statistical information (i.e. chronic conditions, treatment, pre-natal client numbers)
b) Page Two – Service to satellite communities. This page is used for satellite communities that are only accessible by air and are being served by a nurse from a neighboring community/ facility
c) Page Three – Number of current resource positions (i.e. the number of persons who are working in the community who are resourced by MSB directly or indirectly).

The database does not contain all events related to contact with clients, and the reported data are often incomplete and subject to misclassification. The database, in its current form, is not structured to allow individual-level linkage to other sources of data. Some First Nations are not participating in this surveillance system. In terms of access, there is no policy on access to the data by extramural researchers or its cost. It is important to note that the intent of the database is not for research purposes but primarily for financial management.

5.1.8 **Provincial Social Services**

Portions of the previous provincial Department of Social Services (DOSS) was incorporated in April 1999 within the Department of Health and Community Services (HCS) under the regional health care board, Health Labrador Corporation (HLC). This department has built databases for its four major work areas:

A. **Young Offenders Information System (YOIS).**

This electronic system is used to report monthly on the number of young offenders within the province by community and regionally; provincial numbers can then be compiled and reported up to the concerned government departments. The database has been tailored for the use of the department. Information is logged in at the community level and then rests on a server at head office. Access is limited and is obtained by password only. At the community level, access is limited to those workers dealing directly with clients on a need-to-know basis. The District Manager has access on a need-to-know basis. Approval for access can be granted at the provincial level.

Information for this database is collected at the community level by Community Service Workers (CSWs) and Social Workers dealing with young offenders. Data is entered by the CSW or the Social Worker. Information on the young offenders is keyed in as events occur – i.e. for young people already in the system, an incident report requires an update. For young people interfacing with the system, information is entered on entry.

Fields within the system include name, date of birth, file number, community and category (i.e. supervised probation, community service orders, custodial placements – which further include: remand, open and closed custody.

B. **Child Welfare Information System**

This electronic database is also used for community, regional and provincial reporting - i.e. the number of people awaiting adoptions locally, regionally, and provincially or the number of children in protective custody for whatever reason locally, regionally and provincially. The system is housed at the Department of Health and Community Services

in St. John's. Data at the community level are collected and reported manually by CSWs and Social Workers. Information is collected by these staff members as clients enter the system in some manner. Forms are filled out in the community office (and kept on file for future reference) and then forwarded to the department for entering by a data entry officer. Data is updated as events occur or as clients are admitted to a protective caseload.

Fields within this system would include:

- names of foster parents
- date of birth of foster parents
- community residence of foster parents
- names of persons applying for adoption
- date of birth of those applying for adoption
- community of residence of adoption applicants
- names of parents of families who are on a protection caseload
- date of birth of parents on protection caseload
- community of residence
- category of inclusion (i.e. neglect, sexual abuse, emotional abuse, physical abuse)
- date discharged from the protection caseload
- name of child placed with i.e. relatives or others (thus entitling that family to a Child Welfare Allowance)
- names of individuals receiving Child Welfare Allowance
- date of birth of that individual
- community of residence of that individual

C. **Child Care Center Population Movement**

Child Care is defined as the care and supervision of a child for part of a day by a person other than the child's parent, the child's guardian, the child's relative or someone employed by the parent or guardian to care for the child in the child's home.

The Child Care Center Population Movement is a paper system (at the community level), used to record population movement within Child Care facilities in each community. Data are collected manually by Child Care Managers in each community and forwarded

to regional offices monthly. There are three provincial Child Care Centers within the Labrador Inuit region.

Information on population movement includes:

- number of children in Child Care Centers subsidized by the Department of Health and Community Services
- number of one parent families
- number of two parent families
- categorization of profit or non-profit Child Care facility
- age and sex of child

D. Group Home Population Movement

Group Homes are defined as community-based living environments in which young people have access to, and are integrated into the community, but under full-time supervision. The community custody home is the least structured and most socially normal setting available in the open custody service.

The Group Home Population Movement system is a paper system (at the community level), used to formulate reports on movement of clients in and out of the ten (10) Group Home facilities within the province. (Three of these Group Home facilities are in Labrador, with two in the Labrador Inuit region.) Data to feed this reporting are collected by Group Home Coordinators and forwarded to District Managers on a monthly basis.

Information on population movement includes:

- daily count of clients within the facility
- number of males/ number of females
- age of residents within the facility
- number of Temporary Releases (TRs)
- number unlawfully-at-large for the month

5.1.9 Education

The Labrador School Board administers educational services for children from grade kindergarten to twelve in all Labrador communities. This institution has jurisdiction over schools, teaching and support/ administrative staff, and regional program specialists.

It has been reported that community schools do not keep cumulative data from year to year. Rather, records of student numbers, etc are formulated annually on hard copy and forwarded to the School Board office to form the basis for the development of regional statistics.

The annual reports compiled manually at the community level include the following information (categorized by sex of the student):

- # of students enrolled in high school grades
- # of high school graduates
- # of early school-leavers
- # of Kindergarten students
- # of students by grade and age
- # of students by religion
- # of students enrolled in each high school course
- # of Special Education students by category
- # students enrolled / subject Grades K-9
- # students in various subjects in elementary grades
- # of teachers
- # of repeaters Grades 1-9

This annual report is used to justify staffing and programming allocations based on enrollment in various grade and subject levels. Information comes from the various class lists developed as students begin the new school year. Data are put together by clerical staff at the community level and forwarded to the Board office. Local numbers are updated as students enter or leave the system, but reporting to region only occurs annually.

It is expected that some schools within the Labrador region will be utilizing *WinSchool* – a computerized database system – within the next year.

Information from community schools of students who withdraw from school prior to graduating (i.e. early school-leavers) is transmitted at Board level to the Department of Education's Research, Statistics and Planning Division. The Student Withdrawal Information System is able to track students who have withdrawn from high school prior to graduating. This division also keeps a record of year-end course marks for individual students within the High School Transcript Information System. The student identifier within this system is the MCP number.

5.1.10 **Policing**

The Royal Canadian Mounted Police (RCMP) delivers policing services to coastal communities. Some communities have members of the force stationed there at all times, while others have members making visits to the community on a regular basis.

The RCMP maintains three electronic databases for its everyday work. Two of these databases can be accessed through the RCMP administrative system known as ROSS (RCMP Office Support System). It was noted that the data utilized are only as good as the contributing agencies make it – i.e. updating, providing appropriate data, etc.

A. **Police Information Retrieval System (PIRS)**

This occurrence driven system is a Canada wide RCMP system that can be used to query information on any individual who has had any interaction with the force. The system can be utilized to track trends within a community, region, etc. This trend publication can become public knowledge once prepared. All major police forces in both Canada and the US feed into this database and are said to be contributing agencies. Links can be made to retrieve information from this database by contributing agencies. An individual can be tracked within this system by a license plate number and/ or information from the driver's license.

Each community of data origin has a *B code* identifier, so information can be tracked back to that community. Data are entered at the point of origin and then sit on a server in St. John's provincially and in Ottawa nationally. Client files are linked to the attending officer by RCMP regimental numbers. As well, each RCMP detachment has an Originating Response Identifier (ORI) number, which allows for linkages to the Simplified Paperless Universal Reporting System (SPURS) database.

Statistics Canada has access to this database to analyze trends and occurrences nationally.

This database has been specifically designed to meet policing needs. The DOS based system does not allow for mouse usage and some screens are very specific as to responses (i.e. number of characters possible, etc.). Information is taken from files as a client enters the system (i.e. upon interaction with the RCMP either as a complainant, a witness to a crime or as an accused). Data are prepared by the attending officer and then entered by clerical staff. Updates occur as action is taken on a particular file.

B. **Canadian Police Information Center (CPIC)**

This electronic database is also a Canadian wide system, which is accessed by a number of contributing agencies, but is maintained by the RCMP. The detachment ORI number is used as an identifier when queries are made to the system. This database can be queried as to legal status of an individual. The birth date (through the driver's license and license plate) and name are the linkages. Queries concerning individuals might include status as to:

- warrant for arrest
- previous charges
- registration of firearms
- undertakings
- "of special interest"

This system also has a message function in that detachments can send messages/ advisories on an electronic message board to various other detachments across the province, region or country.

This system is prepared in a Windows platform. Various justice related agencies contribute to the information, with Motor Vehicle Registration (MVR) providing the linkages for tracking individuals. Data are prepared and entered by the attending officer and can be entered by clerical staff. Updates occur based on action taken or further occurrences.

C. **Simplified Paperless Universal Reporting System (SPURS)**

This "local" electronic system is said to be the actual file cabinet of the detachment. All local client interactions of any nature are included in this database. Hard copies can be printed out when needed for court and other formal processes. Scoring of this system (based on an extensive scoring classification) is key to effective monitoring of what is happening within the detachment. Linkages from SPURS are also made to PIRS through client files. PIRS can be updated automatically as SPURS is updated.

This system can also produce trends over time. Mayor's Reports are produced monthly for various agencies, outlining occurrences (based on the scoring given at the point of data entry). These reports can also be produced quarterly and will yield a comparison of some particular community to itself over time (i.e. August 1999 vs. August 1998 or vs. July 1998). Comparisons can also be made with other communities within a region over time.

This system can also purge itself of old files after a pre-established period of time.

This database has been especially designed to meet policing needs. The DOS based system has similar components to the PIRS database. Information for the system is based

on investigations and outcomes following. Data are entered by the attending officer and are updated as action is taken or with new occurrences.

5.1.11 **Legal Services**

A. **Labrador Legal Services (LLS)**

Labrador Legal Services (LLS), founded in 1976, has its head office in Goose Bay. This aboriginal organization is largely funded by the provincial government, but is run by a Board of Directors Inuit and Innu population. LLS provides services to aboriginal clients which include: court support and assistance, prison liaison, anti-violence initiatives, cross-cultural training, research, mediation training, community justice workshops, information sharing and advocacy/ lobby effort for communities.

LLS regularly collects information on court-worker assisted clients appearing in court and inmate lists at the Labrador Correctional Centre. This organization also has court dockets on file for the last five years. LLS also houses compiled data from Provincial court records from 1981-1995. This database includes information from various communities in Labrador with data on crimes committed, date of offences, etc. The names of the clients are not kept in the main database but are coded in another data source.

LLS have not yet published any comprehensive reports, but samples of reports that have been used for various purposes are available.

As well, police data have been entered in another database – Labrador Correctional Centre information was completed for some of those years. In addition, Youth Corrections, Child Welfare and some Department of Social Services data have been collected for several years.

B. **Law Courts**

The Law Courts of the Department of Justice maintain an information system known as the Provincial Court Information System. This database provides client information on case management, fines and offense history.

C. **Community Corrections**

The Community Corrections Division of the Department of Justice maintains an information system known as the Community Corrections Information System. This system is able to track clients upon conditional release into the community. The information within this system is not readily available to the public.

D. **Adult Corrections**

The Adult Corrections Division of the Department of Justice maintains an information system known as the Sentence Administration Information System. This system contains information on the sentence given to persons convicted of a crime. The information within this system is not readily available to the public.

E. **Criminal Law Division**

The Criminal Law Division of the Department of Justice maintains an information system known as the Crown Attorney Case Management System. This system contains

information on criminal investigations past and present. The information within this system is not readily available to the public.

5.1.12 **Other Health Information Systems**

A. **Provincial Communicable Disease Control (CDC) Immunization Database**

The Communicable Disease Control (CDC) Program maintains a listing of all immunizations received by individuals from the provincial immunization program. School Health cards, of children who have completed high school or are no longer within the school system, from all communities, are sent to the regional Communicable Disease Control Nurse (CDCN) for cleaning and downloading of relevant Tuberculosis (TB) information. These cards are then sent to the Department of Health and Community Services, Disease Control and Epidemiology Division, St. John's for scanning and placement on CD ROM. Previously cards were microfilmed (those with birth-dates from 1954 to 1966-67) and then made accessible, but cards with birth-dates from 1967-68 have been scanned and placed on CD ROM.

The CD ROM can be accessed by a system known as *File Magic*. Searches are conducted using the date of birth, first name or last name as the locator. This system can be accessed by Community Health staff requiring information on the immunization status of individuals whose cards are no longer held within the Community Health office.

Fields within this database include all information contained on the School Health card i.e. date of birth, first name, last name, parents' names, community, etc.

Scanning each card actually enters the data. A search is conducted by date of birth, last or first name. An actual picture of the card appears as it was in its original form – handwritten, signature of care-giver, vaccine lot number and so on. A print-off of the screen is possible and is often useful if the handwriting is difficult to read.

Cards are sent in yearly by regions and are scanned in batches. The scanning is completed by contract to an external agency, so large batches are done at a time. Old cards are destroyed once data is accessible on CD-ROM or past microfilm. There are plans afoot to have all microfilmed cards put onto CR-ROM as funding permits. It is also expected that this source of health information will be linked to the planned Client and Referral Management System (CRMS) system as funding permits.

All diseases which are notifiable are also reported to the CDC office, utilizing the provincial Notifiable Diseases form. These notifications are then forwarded to the provincial CDC office. A number of the fields are forwarded on, in aggregate format, to National Notifiable Disease Registry at the Laboratory Center for Disease Control (LCDC), Health Canada in Ottawa.

B. **Regional Immunization Database**

The regional Communicable Disease Control (CDC) office at the Melville Hospital in Goose Bay maintains an electronic record of vaccinations given in the region outside of the regularly scheduled program i.e. Rabies vaccines for those in contact with rabid animals, vaccines given to clients travelling outside the country, postnatal Measles, Mumps and Rubella (MMR), Pneumovax, and so on. Records of these immunizations are useful for clients/ caregivers needing access to immunization status from anywhere within the region.

All MMR immunizations are reported to the province on a regular basis; record of other immunizations is kept on the electronic file for future reference.

Microsoft Pro is the electronic platform that has been used to develop the database. Consent for vaccine forms submitted by Community Health Nurses are the source of information for this system. Data are keyed in by the CDCN on a regular basis – usually upon completion of the completed consent form.

Fields within this regional database include date of birth, MCP number, first and last names, vaccine type, date of vaccination, and additional dates if more than one dose of vaccine is required.

C. **Regional TB Database**

The Labrador region over the last number of years has been able to develop its own TB database for access and use by health care providers. This database was developed in 1995 and is housed within the CDC office at the Melville Hospital as a result of a partnership arrangement with the Labrador Inuit Health Commission (LIHC), the Sheshatshiu Health Commission and Health Labrador Corporation (HLC).

This electronic database was originally written in *Alpha 4* and has recently been converted by LIHC into *File Maker Pro*. The conversion was deemed necessary to make the information more accessible, user friendly and to allow for more efficient client follow-up. The database contains information on all clients who have been in contact with TB, either as contacts or as cases. Information is collected by Community Health staff and referring health care providers. Data are keyed in by the CDCN or clerical staff upon receipt.

This regional database contains two sections, one being client information focused and the other is concerned with chemoprophylaxis. The TB Clients section includes the following fields: TB identification number (developed for the system), client name, MCP number, date of birth, home community, ethnic origin, death, date of death, TB skin test

history, BCG history, old TB history, and a history of medications and follow-up. This section houses 1324 records to date.

The chemoprophylaxis section of the database contains 946 records to date. The fields within this record keeping system include: TB identification number, start date for treatment, completion date for treatment, reason for treatment (i.e. contact, case, etc) name of index case if contact, a calculation of treatment duration (i.e. 3.2 months), and a listing of drugs taken.

D. **Client and Referral Management System (CRMS)**

The provincial Department of Health and Community Services (DOHCS) is in the process of developing and implementing a computer system, the Client and Referral Management System (CRMS), to facilitate sharing of client information among health care providers within the Community Health sector.

It should be remembered that Community Health provides a broad range of services to its clients, such as immunizations, child health clinics, addictions counseling and mental health services. Since the recent merger with the Department of Social Services (DOSS), the Community Health sector also includes child welfare, community corrections and family rehabilitative services. This merger became effective in Labrador on April 1, 1999 (during the time of this inventory).

The CRMS is designed to help DOHCS meet two key organizational objectives – client management and referrals. These two objectives are addressed in this single, integrated information system.

CRMS is a client-focused, interdisciplinary tool. A client can be an individual, family, group/ organization, community or population. The client management component

focuses on demographics (including names, addresses, contacts, lifestyles, etc.), service plans (identifying the stakeholders, the client's needs, and the services planned to meet those needs) and programs and services provided to clients.

The referral management component provides for a standardized method of identifying all service requests. This includes three types of requests:

a) those from stakeholders outside DOHCS for service(s) that DOHCS can provide;
b) requests for service(s) on behalf of clients to stakeholders outside DOHCS; and
c) requests for service(s) available within DOHCS.

It is expected that CRMS will contain a number of components, those being:

a) Child Welfare Registration (CWRS) – a system to maintain client and case registration information on services provided through the Child Welfare Program. The primary use is to identify the existence and location of all child welfare files for a particular person.
b) Communicable Disease Control (CDC) – a system to maintain client and communicable disease information (system previously described in **Section 2.9.1**).
c) Child Health Clinic (CHC) – this is a prototype to be used during clinic visits. This system will contain information on immunizations, administered tests, etc.
d) Workload Management Project (WMP) – this system will be used to provide CRMS users with the necessary tool to manage and track client workload.
e) Integrated Support Services Program (ISSP) – a youth profile developed to facilitate interagency (specifically the Departments of Education, Health and Community Services and Justice) cooperation, collaboration and communication.
f) Wait List – a system designed to manage client wait lists for long-term care, with records of information on services needed by the client, favored facilities, etc.

g) Young Offenders Information System (YOIS) – this system could eventually become part of CRMS (system previously described in **Section 2.5.2 a**).
h) Family Assistance Computer Terminal System (FACTS) – this system could eventually become part of CRMS. This system facilitates the administration of Human Resource and Employment's (HREs) Income Support Program.
i) Cervical screening – a system to manage the Cervical Screening Program (see **Section 2.3.1**) and could eventually become part of CRMS.

Some portions of CRMS have been rolled out in the Western and Central regions of the province with positive results to date. Northern, St. John's and Eastern are struggling with the roll-out. The Labrador region has put the service set-up on hold to date.

E. **Addictions Services**

The provincial Department of Health and Community Services (DOHCS), through its regional health care provider Health Labrador Corporation (HLC), provides addictions services to the northern Labrador region. This program utilizes an information system to track client case-loads and to predict programming and service needs. The Clinical Database Management System (CDMS, a provincial system, contains the coded demographic and clinical data on pertinent encounters with acute care facilities, both within the province and at out-of-province facilities. (It should be noted that there is no direct linkage between this system and the aboriginal addictions treatment facility within the region.)

Information on each client using Addictions Services is provided to the system through a demographic profile sheet, which is completed with each individual as they access services. These sheets and the resulting charts, do not contain client names, rather the MCP number is the identifier. If a client does not have an MCP number, the first three

letters of their last name are used. This information is kept on a secure Rolodex system, accessed only by client counselors.

Data are updated by clerical staff on a monthly basis. Client information is keyed into the system on a regular basis, even if clients are a "no-show" – the counselor must fill out a demographic sheet on the client to update the system for all interactions.

Fields within the database include:

- Date seen
- Waitlist date
- MCP number
- Religion
- Place of residence
- Client status (user, family, co-dependent, Adult Child of an Alcoholic [ACOA], child, other)
- Status of service (new, update, readmission, transfer, intake)
- Birth date/ age
- Sex
- Ethnicity (Caucasian, Innu, Inuit, Metis, other)
- Marital status
- Living arrangement
- Number of children and dependents
- Religious upbringing
- Education (highest grade completed)
- Post secondary education
- Employment status
- Type of employment
- Major source of income
- Annual family income
- Occupation

F. Provincial Perinatal Program

The provincial perinatal program, run by the Newfoundland and Labrador Provincial Perinatal Committee at the Janeway Child Health Centre, St. John's, collects, analyzes, interprets and reports on perinatal events. In relation to the follow-up component of the program, information is collected on the infants who are followed, this includes pregnancy and birth information, perinatal risk factors and developmental outcomes.

The Program is currently in the process of developing a Provincial Perinatal database which will collect prenatal, birth and postnatal information on all pregnancies in the province. To date the Perinatal Committee has piloted the prototype at the Grace Hospital, St. John's, (Women's Health Program) and are now beginning to analyze the data. Once this method is validated, it is hoped to move the system to all facilities which provide maternity care within the province.

G. **Occupational Health and Safety**

The Occupational Health and Safety Division of the Department of Employment and Labor Relations, maintains a database on work injuries that result in loss of time at work. Information for this system is obtained from Workplace Health and Safety Compensation Commission (WHSCC) forms completed by the workplace at the time of injury, with additional data provided by the attending health care provider(s). All workplaces must report work related injuries. The *Workplace News*, a newsletter published quarterly by WHSCC, outlines provincial statistics as to loss of time at work due to injuries by affected system. Regional statistics are also available in aggregate format.

H. **Community Health Nursing Information System (CHNIS)**

The Department of Health requires statistical reports from Community Health Nursing (CHN) staff province wide on a regular basis. These reports are submitted by the region to the Department of Health on a monthly / quarterly basis and generally result in provincial reports of regional PHN activity. These types of reports are useful for staffing and program planning by community and region.

Staff at the community level complete Community Health Nursing Information System (CHNIS) forms on a weekly or biweekly basis and forward them to their regional office. Nursing staff are issued a provincial identifier number which travels with them within the province and appears on each completed form. The form requests a region code, an area

code and staff signature. Service provider information is collected using a coded system for the necessary fields, which include:

- District (each community has been given an identifier)
- Date (year, month, day)
- Name (type of service or where)
- Site (nursing office, home visit, school, etc.)
- Nursing service (immunizations, counseling, preparation/planning, health display, screening clinics, etc)
- Class
- Age (individual or group code)
- Sex
- Persons (number)
- Case status (new, revisit, not at home/no show, discharge)
- Referrals (code to indicate which professional referred to)
- Time (length of time taken with the indicated process)

This system will likely be incorporated into the before mentioned CRMS system over time.

I. **Integrated Support Services Program (ISSP)**

The three provincial departments of Education, Health and Community Services and Justice have collaborated on an initiative to facilitate interagency cooperation, collaboration and communication – the Integrated Support Services Program (ISSP). The result of which has been the formation of teams at the community level (in some regions) to support, network on and seek assistance on the needs of children and youth at high risk.

The community team completes a Child/ Youth Profile on each child being followed. This profile is forwarded to the Child Health Coordinator (CHC) who keeps a regional record of the various service needs and special requirements. Thus, for example, from a

compilation of each individual profile, the CHC will be able to report that a region has seventy-five language needs that should be met. In the Labrador region these data are currently held on hard copy. Plans are underway to include the ISSP into the CRMS – but not all areas of the province have been in-serviced on and utilize ISSP.

Child/ Youth Profile sheets are completed by the Integrated Support Services Manager (ISSM) at the first team meeting. Data collected include:

- Community of residence
- School or preschool program
- Region
- School district
- ISSM name
- Date of profile
- Name of child
- Date of birth
- Legal status
- Primary area of need
- Age/ grade
- Behavior
- Compensatory skills
- Well-being
- Personal care
- Program material
- Speech/ language/ audiology
- Technology
- Program

Following the assessment and profile completion, primary areas of need are determined i.e. academic learning difficulty, cognitive delay, gifted, learning disability, developmental delay, and so on.

5.1.13 **Federal Health Care**

At the June 1999 meeting of the Conference of Deputy Ministers (DMs), support was given to proceed with the Network for Health Surveillance in Canada (NHSC), together with an F/P/T (federal/ provincial/ territorial) coordinating body (Health Surveillance

Working Group). The DMs endorsed the recommendations and direction outlined in the document entitled *Proposal to Develop a Network for Health Surveillance in Canada.* This Health Surveillance Working Group reports to the Advisory Committee on Health Infostructure, which in turn reports to the Conference of Deputy Ministers of Health.

A. National Health Surveillance Info-structure

The National Health Surveillance Infostructure (NHSI) is the federal component of the NHSC. It was established in 1997 and over the next three years will involve a transition from a set of pilot projects which build on the concepts of networks and information management as applied to surveillance, to an infostructure which supports advances in surveillance systems undertaken by the various partners at the federal, provincial and local levels.

The mission of the Network for Health Surveillance in Canada (NHSC) is the building – over time and step-by-step – of the relationships, tools and connections needed so that community health decision-makers anywhere in Canada can access, via the Internet, the information needed to better meet national, provincial/ territorial and regional/ local community health needs.

The Network for Health Surveillance will allow the collection, integration and analysis of data from diverse sources to provide information for risk management, i.e. proactive policies to reduce hazards to health, and to allow for faster reaction to disease outbreaks, faulty products, poisonings, etc.

The main thrust over the next three years will be to address the generic needs of surveillance systems through the development of supporting integrated functions such as inventories, metadata, standards, skills development, etc. These activities will be of two types: those that can be implemented at a generic level – (such as portal, inventories, general standards, principles and protocols on privacy and access to data as well as

system administration, database, administration and system maintenance within Health Canada for the common NHSI surveillance environment), and those which will be developed through specific applications in pilot projects (such as specific standards, data development, software development). It should be noted that the intent is to provide tools or to undertake activities which benefit those who actually do health surveillance, community health assessment and/or community health policy.

The NHSI is now comprised of six projects plus the ONHS (Office of National Health Surveillance). The following summaries provide a brief outline of the main objective of each project and the expected deliverables.

Canadian Integrated Public Health System (CIPHS)

The Canadian Integrated Public Health System will link, in a standard manner, data from health laboratories, community health units and other potentially valuable information sources to provide timely information to manage risks to health and to reduce response times between collecting the data and determining that actions must be taken to prevent further harm. It is intended that CIPHS provide direct support to the health community via health information gathering, collation and communications at the local, provincial, federal and international levels, data management in public health laboratories and general health surveillance. Indirect support would take place through provision of data for epidemiology, risk and crisis management; community health policy making, public access to health information and application of health surveillance privacy issues, etc.

The CIPHS is intended to demonstrate the validity and utility of a common data model and data standards for use within a spectrum of agencies in a manner that is effective, timely and cost-efficient. It is a planned suite of integrated computer applications and databases designed specifically to implement a standard mechanism for acquisition, management , and communication of information relevant to community health

surveillance starting with the laboratory and now including case management within local health units/ authorities.

Spatial Public Health INformation eXchange (SPHINX)

The Spatial Public Health INformation eXchnage is an interface for presenting information from existing databases and analyzing and displaying this information in a variety of formats, including mapping, to enhance community health surveillance at all levels. The purpose of this second phase is to assess the feasibility of using this tool across additional jurisdictions, to increase the range of disease and risk factors data-sets, and include an automated alerting function. SPHINX currently enhances access to communicable disease data and contextual information (e.g. waterways) and provides geographical comparisons (data mapping) in order to enhance the ability of health professionals to understand the factors which affect the disease trends in the population.

IM Infrastructure

The purpose of the information management (IM) infrastructure is to provide a unified architecture and approach to core information issues (including providing and enabling access to and information about information), that are common to the work of the NHSC and the projects in the NHSI activities that take place in support of the Network for Health Surveillance in Canada.

There are seven sub-components of the project. These components cover a wide range of information systems, and it is anticipated that health care professionals participating in the NHSC in the next years will expect a combination of information services including these. It is not expected that all sub-components will be designed and fully populated within the three year time frame. Rather, the aim is to provide key services to meet immediate needs, to probe issues that stem from this work, to help users clarify their needs and to help detail further work in design and populating services such as these.

The IM infrastructure is intended to underlie both the development of new projects as well as in the operations of the Network for Health Surveillance in Canada (NHSC). There will be some common requirements among various health surveillance initiatives, for example the need for standards and Geographic Information System Infrastructure (GIS) functionality. The purpose of the infrastructure is to provide a common, integrated approach to meet these requirements. The NHSI infrastructure will also provide and enable access to information and information about information.

Skills Enhancement for Health Surveillance (SEHS)

The purpose of this project is to assist partners in acquiring the skills necessary for the delivery of effective surveillance functions. The project also has the potential to disseminate skills which will reinforce a standard approach to information management and methods models in surveillance; to raise awareness of issues in the analysis and interpretation of health surveillance data and increase the likelihood of cooperation in producing quality data in the future. It will also increase the probability of widespread participation and use of the current tools provided by the pilot projects, and thus the potential for meaningful national data.

Addressing Health Surveillance Data Gaps (AHSDG)

This project was initiated to deal with the issue of health information which is currently not collected or is inaccessible, by creating Internet-based capabilities which support the collection, analysis, interpretation, and dissemination of health information. The project is initially composed of three components which address the development of tools and connections in the areas of: risks from drugs used in pregnancy (Mothernet), health information contained in coroners' reports, and the improvement of injury surveillance.

Office of National Health Surveillance (ONHS)

The key objective of this project is to help the NHSC to develop a suite of web-based surveillance tools and infrastructure to enable timely information exchange and analysis, in a secure environment, using agreed-upon standards for information dissemination, and supporting timely dissemination of practical information that is useful for community health policy and program needs. As well, the office will provide a secretariat function to the Health Surveillance Working Group and support the strategic directions, business, options and other aspects of the overall direction of the Network for Health Surveillance in Canada.

B. **Health Information System (HIS)**

In 1988, the Ontario Region of Medical Services Branch (MSB) analyzed its collected health data. The analysis confirmed the existence of inconsistencies in data collection practices across the region. It was decided that a comprehensive Health Information System (HIS) should be developed therefore standardizing health data collection amongst First Nations living on reserve.

In 1990, an Extended Working Group was established to oversee the development of the HIS. The HIS was initially viewed as a Nursing Management System, however, as development progressed, its scope eventually broadened and became a system to facilitate the delivery of health services to aboriginal communities as well as a comprehensive epidemiological database that could be used for priority setting, planning and evaluation purposes. The Ontario system formed the basis of the system that is being put forward for national use by all aboriginal groups.

Concurrently with this progress in the Ontario region, in 1994/95 MSB consulted extensively with all Canadian First Nations in order to identify the latter's requirements in the areas of health information and information technology. A report, entitled "Strategic Planning for Health Information Management" was subsequently produced

and identified critical weaknesses in the areas of community-based health information systems as well as overall information technology knowledge.

The HIS, which has gone through a number of revisions, is comprised of eight major subsystems (i.e. Client Information, Immunization, Reportable Diseases, Psychosocial, Chronic Diseases, Maternal Health, Environmental Health and Abuse Profile). The system also contains five minor (linked) subsystems (i.e. Test/ Exam, Medication Allergy/ Adverse Reaction, Medication, Public Health Education and Client Mortality Information).

The primary objectives of the Health Information System are to:

a) eliminate duplication, reduce the number of forms, and standardize reporting;
b) reduce manual tasks of recording and extracting information;
c) standardize health information collection and recording practices;
d) increase the reliability of the health information;
e) improve the flexibility and storage of health information;
f) reduce the amount of time required to complete reports;
g) improve program planning and evaluation capabilities at the community, zone and regional levels;
h) facilitate a proactive rather than a reactive approach to the management of community health issues; and
i) empower First Nations communities to establish program priorities, which are particularly relevant for health transfer.

It is anticipated that as First Nations communities across Canada assume control of the delivery of health services, the computerized Health Information System will become an integral part of the program planning process. By having a direct access to and ownership of their own health data, aboriginal communities will be able to plan more effectively for the future.

This client-based system contains numerous fields of sensitive client information in the eight systems. Information can be retrieved about individual client health on a need-to know basis and numbers of clients with conditions can also be retrieved (i.e. number of clients with hypertension in a certain community).

C. **Canadian Institute for Health Information (CIHI)**

Since 1994, the Canadian Institute for Health Information (CIHI) has played a critical role in the development of Canada's health information system. CIHI is a federally chartered but independent, not-for-profit organization, responsible for developing and maintaining the country's comprehensive health information system. It brings programs, functions and activities from The Hospital Medical Records Institute (HMRI), The MIS Group, Health Canada (Health Information Division), and Statistics Canada (Health Statistics Division) together under one roof. The Institute delivers the knowledge and develops the tools to advance Canada's health policies, improve the health of the population, strengthen the health system and assist leaders in the health sector make informed decisions.

CIHI operates from its offices in Ottawa, Toronto, Vancouver and Edmonton. Institute core functions include:

- Identifying health information needs and priorities;
- Collecting, processing and maintaining data for a comprehensive and growing number of health databases and registries, covering health human resources, health services and health expenditures;
- Setting national standards for financial, statistical and clinical data as well as standards for health informatics/ telematics; and
- Producing and disseminating value-added analysis.

Through the pursuit of these primary functions, CIHI helps its many clients to make sound health decisions based on quality health information. Stakeholders include ministries of health, health care facilities, health-related organizations and associations, the research community, private sector and the general public.

CIHI offers the following services:

- Analysis and consulting – products and services helping health care organizations and governments manage care for patients, treatment and facilities.

- Data holdings – extensive databases and registries on health expenditures, services and professionals.
- Education – CIHI offers its clients two workshop series – Basic and Advanced, as well as Other Educational Opportunities (e.g. provincial initiatives, customized education and conferences). These services help clients use CIHI health information products more effectively.
- Publications and reports – reports, booklets, and information about health care in Canada, taken from CIHI's work in standards, data and analysis.
- Standards – guides and protocols covering management of health services, technology and classifications to ensure an integrated system of health information in the country.

Table 5.1.13C **Data Holdings of the Canadian Institute of Health Information (CIHI)**

Health Expenditures Databases	
Annual Hospital Survey (AHS)	National Health Expenditures Database (NHEX)
OECD Health Database (Canadian Segment)	
Health Professionals Databases	
Health Personnel Database	Registered Nurses Database
National Physician Database (NPDB)	Southam Medical Database (SMDB)
Health Services Databases	
Databases	**Registries**
Ambulatory Care Database	Canadian Organ Replacement Register (CORR)
Discharge Abstract Database (DAD) and Morbidity Database	National Trauma Registry (NTR)
Hospital Mental Health Database	Ontario Trauma Registry (OTR)
Ontario Chronic Care Patient System	
Therapeutic Abortions Database	

CIHI data holdings are key to its health information activities. The Institute's databases cover a broad range of health domains and make it one of the most comprehensive single data sources in the country. Plan subscribers are entitled to a full range of services, including data quality and processing, client support and direct access to the data they submit.

Mining of CIHI databases is managed through two services. Data retrieval on CIHI's largest database, the Discharge Abstract Database (DAD), is managed through the

Special Needs Analysis Program (SNAP). Information for the DAD is received directly from participating hospitals (about 85% of all hospital inpatient discharges in the country). This is about 4.3 million records annually. Data files for the remaining hospitals are submitted by the appropriate province or territory. Data disclosure is determined by CIHI's Privacy and Confidentiality Policy. In some instances, CIHI and Statistics Canada manage release of information jointly.

5.1.14 **The Moravian Church in Labrador**

The Moravian Church serves the communities of Nain, Hopedale and Makkovik on Labrador's north coast. The community of Rigolet is served by the Anglican Church of Canada and Postville is served by the Pentecostal Assembly of Newfoundland. The Moravian Mission has kept records on its parishioners since coming to Labrador in the 1700s. A number of these records are kept at the Moravian Mission in each community, while still others are kept at the Goose Bay parish. Information has also been kept on communities long since relocated such as Okak, Nutak, and Hebron. The information in the Church Books is kept in three categories pertinent to this inventory and will be described as follows.

A. **Baptismal Records**

This hard copy information system contains data about each parishioner as they are baptized into the church. All information, obtained from the parents or guardians at the time of baptism, is logged in manually by the Minister or Lay-Minister. Data from these records are utilized to prepare Baptismal certificates, replacement records and accounting of numbers of baptisms in annual church reports.

Fields contained within this database include:

- Baptismal number
- Child's name
- Parents' names
- Date of birth
- Place of birth

- Date of baptism
- Place of baptism
- Baptism performed by whom

B. **Persons Joined in Holy Matrimony**

Information for this hard copy information system is gathered from the applicants as they come to be married and is logged in manually by the Minister of Lay-Minister. Data from this system are used to prepare Marriage Certificates and to report numbers of marriages for the year in the annual church report.

Fields contained within this database include:

- Number in the marriage register
- Names of both parties
- Date of birth of both parties
- Age of both parties
- Places of birth
- Status of both parties (single, widowed, divorced)
- Date of marriage
- Marriage performed by whom
- Government license number
- Names of witnesses

C. **Persons Departed this Life**

Information to be included in this hard copy information system is obtained from previous church records, family members of the deceased and the attending health care facility and/or physician. The data are logged in by the Minister or Lay-Minister and are used to assist the Nursing Station or Hospital in completing the Death Certificate; as well, numbers of deaths per community are quoted in annual church reports.

Fields contained within this database include:

- Number in the death register
- Baptismal number
- Name of the departed
- Date of birth
- Age (age is quoted to the exact day, month and year)

- Date of death
- Location of death
- Cause of death
- Place and date of burial
- Burial performed by whom

5.1.15 **Municipal Government**

Municipal Councils currently exist in each community of coastal Labrador. These Councils are generally run by a volunteer group of elected officials, with services being administered by salaried support staff. The Councils maintain hard copy information on and about its constituents to generate the following products:

a) population listing of all individuals living in the community;
b) a Municipal Voters list; and
c) a Municipal Tax list (both individual and business).

Information on town members is gathered from a number of sources:

a) Community Public Health Nursing Birth Book
b) Moravian Church records – births and deaths
c) Local community knowledge of in and out migration
d) Formal queries of agencies when staff transfer in or out of the community (those queries often yield listings of staff members, but does not provide information on the families of these staff members).

Lists of individuals in various age groupings are kept on hard copy, the breakdown being:

a) 0-17 years
b) 18-64 years
c) 65 years and over
d) some means of indicating disabled.

The fields within the hard copy system contain the community member's name and date of birth where available. Some Community Councils are able to keep the community listing in a table format on *Windows 95*. Electronic analysis is not possible in this or hard copy format, but analysis can and is undertaken manually. Information is added to the system by clerical staff as it becomes available as often as possible, but at least annually to facilitate the compilation of a Taxation List.

These data are public property and are shareable between agencies.

5.1.16 Newfoundland and Labrador Center for Health Information (NLCHI)

The Newfoundland and Labrador Center for Health Information (NLCHI) established its office in 1997 and has staff in three locations throughout the island portion of the province. Three departments work within the center and include: Product Development, Standards Development and Communications.

NLCHI has been mandated by the provincial government to develop an enhanced health information system for the province. This system will link hospitals, long-term care facilities, doctors, pharmacists, and health and community services within each health region.

NLHCI is also responsible for developing and promoting standards for health information preparation and releasing information products, as well as improving access to consumer health information. The Center employs a team of health information consultants, who are responsible for the development of an enhanced health information system for the province, and the preparation and dissemination of health information products put together by NLCHI.

This team uses information from the Clinical Management Database System (CDMS), the Canadian Institute for Health Information (CIHI), and other sources to prepare reports for widespread release within the province. The following reports have been released by the Product Development Division (NLCHI web page, 2000):

a) Live Birth Trends For Newfoundland and Labrador, A Six-Year Profile, 1992-1997
b) Community Health Regions – Demographic Profiles
c) Surgical Day Care Utilization Profile, Newfoundland and Labrador, 1996/97-1997/98

d) Regional Acute Care Utilization Profile, Hospital Separations and Length of Stay Statistics, June 1998
e) Regional Health Status Reports, March 1998
f) Statistical Summary, Births and Deaths, 1995, February 1998
g) Mortality in the Province by Health Region, A Ten Year Profile, 1986-1995
h) A Report on the Health Status of Newfoundland and Labrador, Tables and Figures, December 1997

A NLCHI newsletter is also published on a six weekly basis, providing ongoing information on the development of the Health Information System and other products. The Center will also respond to specific inquires from regions or individuals.

A limitation to the information collected by NLHCI concerning Labrador is that the data is collected in a generic format, in that all groups are lumped together. Therefore the aboriginal health care organization is not able to receive information or reports on the health status of its particular clientele from this current data format. This clumping has been recognized as a limitation by a number of individuals and is to be addressed by NLCHI.

A. **The Unique Personal Identifier (UPI)**

December 1999 saw the Newfoundland Center for Health Information (NLCHI) and the SmartHealth Consortium complete the project framework, the determination of the functional specifications and resource requirements for the Unique Personal Identifier / Client Registry phase of the proposed provincial Health Information Network (HIN). Upon completion of this work, NLCHI will present the findings to the Minister of Health and Community Services. Pending final approval from the provincial government, NLCHI will proceed with the design and implementation of the UPI/Client Registry (NLCHI, December 1999).

The UPI is a number given to a person once in a lifetime, either at birth or upon moving to the province. The number will not change if the last name is changed, or upon returning to the province to live after a period of residency elsewhere. Every person accessing the health system will have a unique personal identifier, regardless of his or her eligibility for MCP.

The MCP number will be the de facto unique personal identifier. The MCP number will continue to be used in all paper and electronic charts, and in reference to a patient or client. There are people, however, using the Newfoundland and Labrador health system who do not qualify for MCP. These people will require a unique number as well. In order to facilitate the operations of the information systems that form the proposed health information network, the UPI/Client Registry project will create a new number for every person accessing the health system. There is no intention, at this time, to move to the new number. Such a move will be discussed with all stakeholders beforehand.

The *shadow* unique number will be part of the client registry. It is not necessary, and with some systems it will not be possible, to access a person's record using the *shadow* number. The record will be accessible by using the MCP number or the person's name. Some users have requested that they have access to this new unique identifier, and this is presently being studied. The *shadow* number will not be required for billing or admitting purposes.

Development of the UPI will require creation of a registry of valid demographic information about each resident of the province, i.e. the client registry. The client registry will draw upon data in the existing MCP database, some of the health regions' databases, and individual contact with residents to develop a registry containing demographic information (name, date of birth, address, etc.) for all people accessing the health system. The client registry will be available seven days a week, 24 hours a day to allow for immediate registration of all service recipients, including newborns, and confirmation of eligibility for MCP.

Some of the issues being studied during this stage of the project include how to "clean up" the MCP database, what demographic information should be held in the new registry, and whether a new health card is required now or later in the development of the HIN.

5.1.17 **Labrador Inuit Data Sources**

In addition to the various federal and provincial data sources described, Labrador Inuit have also begun to develop their own data sources which could be utilized in the health assessment of northern Labrador.

A. **Membership**

The Labrador Inuit Association (LIA) maintains an electronic database on the 4800 members who are its constituents. This listing is held on the *Panorama* platform and is used to verify benefits (i.e. Non-insured health benefits) or other organizational qualifications (i.e. hunting license eligibility, post-secondary support qualification, and so on).

Individuals wishing to apply for membership in the association must fill out an application, which then becomes the source of information for the database. Membership applications for newborns are completed by the parents of the children. Applications are completed with the assistance of the Fieldworkers at the community level and then forwarded to the head office for consideration and review. The Board of Directors of LIA reviews all membership applications (except those newborns whose ancestry is clear-cut) and grants approval where appropriate. Once membership has been granted, the individual is issued an LIA membership number (these numbers are generated in Ottawa once approval has been granted) and is then eligible for benefits and consideration under

all programs and services. Information is keyed in by the Membership Clerk as new members are added or as membership is revoked.

Fields within this database include:

- Individual's full name
- Date of birth
- Address
- Sex (male or female)
- Membership revoked or not revoked
- LIA identifier number

Numbers from this membership listing are used as the unique identifier for many of the programs and services delivered by LIA through its affiliates.

B. **Health**

The Labrador Inuit Health Commission (LIHC) as the health care affiliate of the Labrador Inuit Association (LIA), offers a number of programs and services to the members of LIA. Within these programs a number of data sources have evolved in hard copy and/or electronic format to enhance service delivery and program evaluation.

Non-Insured Health Benefits (NIHB)

The Non-Insured Health Benefits (NIHB) department, operated within the Labrador Inuit Health Commission (LIHC), maintains a number of data sources to track and monitor service delivery. These data sources are maintained by the NIHB staff and are updated as clients interface with the health care system. The Patient Statistics database is pertinent to this project.

This database currently exists in electronic format on the *Alpha 4* platform since 1991 and on the *Panorama* platform prior to 1991. Information to feed this system is provided in written reports from the referral system at the referring hospital. The information contains data on patient movement, escorts to travel, location of referral, accommodation while receiving treatment, and services provided at the health care facility.

Information from this system is used for reporting purposes to Health Canada on a quarterly basis.

Addictions Treatment and Administration

Saputjivik, the Labrador Inuit Alcohol and Drug Abuse Treatment Center, maintains two electronic data sources to monitor and evaluate service delivery and client care – an administrative database and a client centered database. Standardized information is collected by the service provider on persons receiving service, and the type of service provided through its Treatment Activity Reporting System (TARS). Required quarterly reports to the National Native Alcohol and Drug Abuse Program (NNADAP) and to the LIA Board can be compiled by this system.

Information to feed this system is provided by the pre-admission forms completed by clients prior to admission to the center. Data are entered by clerical staff as clients are admitted to the center. Records have been kept dating back to 1987.

The information collated in the client database is pertinent to this project. Fields within that database include:

- Intake / Discharge information
- Client's assessment
- Substance abused
- Significant others

This database is individualized, but aggregate numbers can be complied from the reporting system. The LIA number is not the unique identifier number within this system; instead clients admitted to the program receive a client number as the identifier.

Mental Health

The Labrador Inuit Health Commission's Mental Health Program supports a number of electronic data sources which are useful to the monitoring of health status within the region. These information systems reside on the *Alpha 4* platform, with data entered in batches as completed forms accumulate. Data to feed this system are collected in each community by Community and Mental Health staff who are interfacing with clients.

The LIA number is the unique client identifier within the four active Mental Health systems (as listed below). Aggregate numbers from these data sources are used for reporting purposes, as justification of funding allocation requests and to guide the delivery of client service and program needs.

i) Counseling Database

The Counseling database, an individualized system, holds some 1,000 plus records. Fields within the system include:

- LIA number
- Date of birth
- Age
- Sex (male or female)
- Initial contact with counselor
- Referred by
- Referral date
- Previous counseling
- Presenting problem
- Number of sessions
- Status (ongoing, discharged, referred, did not attend)
- Month of discharge

ii) Crisis Line Database

This internal database holds a small number of files and is active for only one community. The database is used to document numbers of calls to the community Crisis Line and the reasons for the calls from 1993-97. Fields within this database include:

- Number of calls and receiving agency

- Categorization of suicidal calls
- Categorization of non-suicidal calls
- Age and sex of caller
- Referral to
- Number of cases involving alcohol

iii) Crisis Response Database

This internal database holds a small number of files and is active for all Labrador Inuit communities. The database is used to document response to crisis incidents in the community of concern from 1993-98. Fields within this database include:

- Community
- Date of incident
- Victim's LIA number
- Age of victim
- Sex (male or female)
- Incident type
- Method

iii) Intentional Injuries Database

This internal database holds a small number of files and is active for all Labrador Inuit communities. The database is used within the mental health department to document any intentional injuries and to link these injuries to crisis response and its management. Fields within this database include:

- Community
- Month
- Victim's LIA number
- Date of birth
- Age
- Sex
- Type of incident
- Method
- Alcohol/ drugs involved
- Crisis response management

Community Health

i) Community Profiles

The Labrador Inuit Health Commission (LIHC) annually requires the completion of Community Profiles from each LIHC community team. These profiles contain information on community demographics, education, community service base, communication, housing, water and sewer systems, garbage disposal, the health care system, transportation and health status. All information is population based rather then individual specific.

Information for the compilation of these profiles is gathered by the Team Leader and team members from various agencies within the community. Profiles are completed annually and forwarded to the Community Health section of the Health Service Department. These profiles are kept in hard copy and have been generated in an electronic operating system i.e. *Windows 98*. Upon receipt, each individual profile is formatted onto a larger document, where each community's data can be compared to that of the others. This type of formatting is especially useful when planning and evaluating program service delivery and when justifying and applying data to proposals for program consideration and funding.

The health status section of the profile is especially useful in that all the indicators are concerned with live births, pre natal conditions and postnatal outcomes. These indicators are also given in a comparison manner i.e. data from the previous year compared to data from the reporting year.

Table 5.1.17i) **Community Health Profiles – Health Status Table**

Indicator	**1999**	**2000**
Number of live births		
Number of non-hospital/ Nursing Station deliveries		
Number of still births		
Number of teenage pregnancies		
Number of births to teen mothers		
Number of deaths (total any cause)		
Number of deaths if infants less than 1 year of age		
Number of babies less than 1500 grams		
Number of babies 1500-2499 grams		
Number of babies 2500-3999 grams		
Number of babies 4000-4499 grams		
Number of babies 4500 grams or more		

ii) Birth Books

Each Community Public Health Nursing (CPHN) office of LIHC maintains a hard copy record of births for the community. This information is compiled by CPHN staff with data obtained from the Live Birth Notification Form completed by the admitting health care center at the time of delivery. Data are updated as births occur in and for the community. A number of coastal communities have information dating back to 1977, but all communities have information dating back to 1997.

Information from this database is used for reporting purposes (i.e. Health Canada Community Workload Increase System – CWIS, Canada Prenatal Nutrition Program – CPNP, and so on) by appropriate staff members.

Fields within this database include:

- Birth number for the calendar year
- Date born
- Baby's name
- Sex (male or female)
- Parents
- Weight in kilograms
- Apgar score at 1 and 5 minutes
- Place of birth/ Comments
- Age of mother
- Type of delivery
- Gestation
- Breast-feeding (Yes or No)

iii) Death Books

Each Community Public Health Nursing office of LIHC maintains a hard copy record of deaths for the community. This mortality information is compiled by CPHN staff with data obtained from the Death Certificate completed by the health care center at the time of death. Data are updated as deaths occur, which are directly related to the community. A number of coastal communities have information dating back to 1977 or earlier, but all communities have information dating back to 1997.

Information from this database is used for reporting purposes (Health Canada, Community Workload Increase System – CWIS, provincial reporting, Municipal Councils, and so on) by appropriate staff members.

Fields within this database include:

- Death number for the calendar year
- Name of client
- Date of birth
- Date of death
- Age
- Next of kin

- Relationship of next of kin
- Immediate Cause of death (and all listed causes where available)

C. **Post-Secondary Student Support Program (PSSSP)**

The Post Secondary Student Support Program (PSSSP), administered by the Labrador Inuit Association (LIA), maintains a program specific electronic database at their head office in St. John's, Newfoundland. This system has been developed on the *Fox Pro* platform (DOS base). It is projected that this system will have to be totally revamped as portions of the system are not working as well as they should. The program manager is looking to *Excel* or *Microsoft Access* as potential replacement platforms.

Information to feed this database is acquired from the application for PSSSP funding. All data are also kept on hard copy and manual analysis is possible when the current database will not perform the required functions. All students who receive funding under the PSSSP program are in this database – part-time, full-time, distance education, and so on.

Data are entered at the Education Office in St. John's by program staff on a regular basis, as school is governed by semesters and updates are required for each coming semester and for annual reports. Student transcripts are used as an update source from one semester to the next. Information from the system is used to formulate progress reports in individual students and on the program in general (for funding purposes and to report to the Annual General Meeting of LIA).

Fields within this database include:

- Name
- Date of birth
- Sex (Male or female)
- LIA Membership number
- Current address
- Permanent address

- Martial status
- Income source
- Spouse's income source
- Number of dependents
- Names of dependents
- Education plan

D. **Employment Support Services**

Torngait Services Incorporated (TSI) supports an electronic database on skill levels of Labrador Inuit. This database is not current and is used for the business of TSI only. The data were gathered in 1995 and continued to be gathered to date as individuals applied to work for TSI in the mining industry. Individuals on the database are categorized by community, trade and field of interest. The database does not contain information on all Labrador Inuit Association (LIA) members, only those who expressed an interest in the mining industry.

These data, a joint collection effort of Diamond Fields Resources/ Inco and TSI, were acquired through several methods:

a) workshop sessions;
b) letters sent out to members of LIA suggesting forwarding resumes and letters of interest for employment in the mining industry;
c) TSI staff setting up in coastal communities and having interested individuals come in with their resumes or to discuss their fields of interest;
d) notices about the initiative posted in all LIA field offices; and
e) information about the initiative being posted on the roll-up (community television channel) in each community.

These data, about LIA members and their skill levels, are used when seeking to gather a listing of the trades/ occupations/ skill levels available within the region. It has been formulated to facilitate matching of TSI job perspectives / opportunities with members of LIA.

These data, collected in 1995-9, are held on *Microsoft Access*, though hard copies of the resumes are still kept on file. There are estimated to be some 1200-1500 individuals on

the database, although there may be some duplicates, which resulted as members sent in updated resumes. Those resumes sent to TSI from 1997 to the present are held in hard copy only. The expense of keeping the information system when little hiring has been occurring was not seen as a cost effective undertaking. Data are currently analyzed manually as the database is incomplete. The primary locator or unique identifier in this system is the Social Insurance Number (SIN).

Fields within this database include:

- Social Insurance Number
- Name
- Address
- Schooling (grade and year completed, school name, school town, school province)
- Date of birth
- Community of birth
- Sex (male or female)
- Additional Information (Health concerns, health specifics, mother tongue, number of dependents, additional information, date of filing)

E. **LIA Training and Education Database**

The Labrador Inuit Association (LIA) has developed a skill and training database so that the Association would have readily accessible information on funded training programs taken by its members. These programs include degree and graduate programs, diplomas, certificates, or any other funded educational opportunities. The database also includes the work skills listing housed at Torngait Services Incorporated (TSI), which readily compliments its educational components.

Three information systems operate within this database, those being: membership, education, and work skills. The membership system was incorporated directly from the LIA membership listing. The education system was built from various informational

sources and the work skills system was transferred from Diamond Fields Resources/ Inco database – which is similar to, if not identical, to that housed at TSI.

The fields within this database include:

a) Membership
- LIA number
- Last name
- First name
- Date of birth
- Community of registration or community of residence

b) Education
- LIA number
- Education identification number
- First name
- Last name
- Community
- Type of training
- Award (i.e. Bachelor's degree, certificate, diploma)
- Additional information (i.e. duration of training, date of program, etc.)

c) Work skills
- LIA number
- Name
- Date of birth
- Related courses taken
- Work experience

This database is developed in *Microsoft Access* format. Information for the system has come from Inuit Pathways, the Post Secondary Student Support Program (PSSSP), and Diamond Fields Resources/ Torngait Services Incorporated (TSI). Data were entered by the individual setting up the database – no one else has been trained to input the data. Information on individuals is updated as new data become available. The system has not been updated since July 1999.

This system can be used to answer questions such as: How many people in a specific coastal community have had training in the mining industry? How many people within the LIA membership have completed education degrees?

5.2 **Chapter Summary**

This inventory is evidence that there is a great deal of information available on and about Labrador Inuit. The information exists in many formats and has been developed for various uses. A review and systematic evaluation of this inventory is presented in the next chapter.

CHAPTER SIX: Results

6.0 Introduction

This chapter will describe the process of choosing a suitable health status monitoring model, the results of the data information sources review, the elimination of those sources that are not currently useful and the rating of those that remain.

6.1 Choice of Health Status Monitoring Model

The following table outlines the population health models reviewed and the selection criteria used to choose the most suitable model, as developed in Chapter Three, page 57 (Health Canada, 1999; Health Information Management Working Group, 1998; ITC, 2000).

Table 6.1 - **Reviewing Population Health Models Using Selection Criteria**

	Selection Criteria				
Model	**Built by Consensus**	**Close match to required organizational indicators**	**Indicators within the model are generally available in the region through currently available data sources**	**The model is readily adaptable for use by the region**	**Resources are available to adapt this model for use in a timely fashion**
A - POPULIS	No – the Manitoba Model is mainly administrative in nature	No	No	No	No
B – WHO Strategy of Health for	Yes – formulated by a short-term	Not clear	Not clear	Not clear	Not clear

All by the Year 2000	working group				
C – CATCH	Yes	No – many more indicators than currently required	No	No	No
D – Turnock and Handler's Conceptual Framework	No	No	Not clear	Not clear	Not clear
E – Healthy People 2000	Yes	The indicator set is not broad enough to encompass all those required by the organization of concern	Yes	Yes	Yes
F – Conceptual Framework (Hancock, Labonte and Edwards)	Yes – consensus building is a guiding principle of this conceptual framework	No – much larger than currently required	No	No	No
G – Canadian Institute for Health Information (CIHI)	Yes	A reasonable match	Generally available	Yes	Yes

Model A: POPULIS – There is much to learn from the Manitoba Health Information System. In evaluating the development of the model, Roos and her colleagues describe methods used to compare health status, various key indicators and hospital use. These lessons have been useful to this project and the suggestions will be used in developing indicators for our region. But, a wealth of administrative data is the foundation of this

model – administrative data that is not as well developed or as accessible within the region of concern.

POPULIS also contains a wide range of health status indicators – more so than all other models investigated. The model was able to draw on linked health service utilization data, an advantage that our region does not have. As well, the development of the original sections of the system took a great deal of time and expertise – our region would not presently have the resources necessary to develop such an extensive project.

Model B: WHO Strategy of Health for All by the Year 2000 – The Report on Health in the Mersey is a source of valuable background information to the project of concern. The methodology of the Mersey project, the five topic areas of data identified and the process undertaken to review the health of the population within the Mersey region are similar to that undertaken for this project. The methodology included: an identification of available and missing data, and a synthesis of information from different databases relevant to health promotion. In addition to the identification of health service data, it also involved the identification and use of essential non-health service data bases such as those relating to education, social services and so on. Methodological comparisons can be made.

The twelve priorities for health in the region were unfortunately not as broad as are required in this geographical region and are health promotion directed. This project is seeking a broad health indicator framework to describe and consistently measure health status.

Model C: CATCH - CATCH is a comprehensive and multifaceted health status monitoring system with a great deal to teach researchers in the topic area. It includes a large number of health indicators from multiple sources, with the capability of producing a rank-ordered community problem list. For inclusion, each indicator must be uniformly collected, available at the community level, and reside in an existing public database. These are similar inclusion criteria placed on health indicators used within this project.

CATCH is large, labor intensive and slow. Its developers have recommended that the system become automated i.e. computerized. This type of large system, while outlining excellent examples of comprehensive indicators might require more resources than are available within the region of concern at this time.

Model D: Turnock and Handler's Conceptual Framework - The Turnock and Handler conceptual framework for monitoring population-health advises public officials to deliver services that are truly useful to the improvement of health. The development of a community health profile is the foundation of the model. The authors strongly suggest a public consultation process whereby community members are informed and involved in the improvement of their own health and health conditions. Turnock and Handler suggest that health officials be more concerned with *doing the right thing, rather than doing things right.*

This type of framework is useful for consideration as the current project evolves. It prods us to remember that measuring health is more than a consideration of numbers, it is equally as important to query the performance of health care organizations based on measurement results.

Model E: Healthy People 2000 - The Healthy People 2000 model of population health is useful to review and explore in light of this particular research project in that:

a) the health indicator set was developed using data that are readily available and that are commonly used in community health;
b) the core indicator set was developed using a consensus approach;
c) indicators were intended to ensure data comparability and to facilitate use by community health agencies; and
d) modifications to existing data collection systems were recommended.

Unfortunately, this model does not offer a sufficiently broad range of health status indicators as other possible models. While the indicators required within this model are

readily available within the region, more indicators are needed to satisfy the remaining organizational data requirements.

Model F: Conceptual Framework (Hancock, Labonte and Edwards) - The framework put forward by Hancock et al offers much to our project. While the authors agree that there is merit to the development of a reasonably standard set of core indicators that can be used for comparison purposes nationally, it is more important that the community select measures that matter if indicators are to count (i.e. have an impact) in the life of the community. The criteria for selection of indicators will be helpful if and when the region of concern reviews and comments on those chosen to measure health status.

This project did not begin with community consultation, but rather began with an environmental scan of the state of data sources available and then proposed a set of indicators that might be a useful starting point. Consultation with the population of concern would be another logical step in the process – after determining whether data sources are available to meet measurement needs. According to Hancock et al, this project started in the middle of the process – the organization of concern will be consulting our clientele when a product (i.e. measurement tool) is available to take forward for deliberation. Thus one of this model's guiding principles have been violated from the outset.

And while Model F is a wonderful example of the self-determination process (especially important for an aboriginal health care group), it does contain a larger number of health indicators than can reasonably be worked with at this time or stage in the developmental process. As well, much of the information required for the indicators have yet to be available within our region. Thus the Hancock et al model cannot presently be the model of choice – governance and civic-ness might be future indicator categories to explore.

Model G: Canadian Institute for Health Information (CIHI) - This population health model is especially useful to the research project in that:

a) initiatives already undertaken within the region, province and at the national level have been taken into account;
b) a broad range of health status indicators have been selected for inclusion within the model;
c) readily available and comparable data will be utilized; and
d) a consensus approach to core indicator selection was utilized.

As well, the health status indicators within the CIHI model are able to match the minimum data sets required to provide information for the population of concern (please refer to **Appendix A**). A full list of indicators was identified and categorized according to the CIHI Report (please see **Appendix C**). The MSB 1998 Health Information Management Analysis of Existing Data Holdings was also used as a resource to this indicator set.

It is also important to note that Inuit Tapirisat of Canada (ITC), the national Inuit political body, confirmed the CIHI Health Indicator Model in their work on Evaluation of Models of Health Care Delivery in Inuit Regions (ITC Draft Report, August 2000). This confirmation, released during the thesis-writing portion of this project, should result in data comparability across Inuit Canada over time.

6.2 **Results of Key Informant Interviews**

A review of health and social stakeholder agencies internal and external to the region resulted in a listing of thirty (30) key informant agencies to be contacted as the basis for the data source inventory.

Initially nine (9) agencies (30%) responded, leaving the researcher to contact the remaining twenty-one (21) agencies individually to request an interview to review data and collection systems. The majority of agencies contacted agreed to an interview following an additional explanation of the process, yielding a total of twenty-two (22), that is 73% of respondents/ agency representatives. Eight (8) respondents/ agency representatives (27%) did not choose to report in any manner. (Information about non-respondent agencies information sources were researched through other means – i.e. Internet, document reviews, articles, etc. and added to this inventory).

6.3 **Reviewing the Available Data Sources**

This section of the project will list and categorize selected data sources for conducting health status monitoring within the Labrador Inuit region, based on the informational needs of the chosen indicator set and those of organizational programs and services. A scaling method, formulated from the conceptual and analytical framework of **Chapter Three**, will be used to review these available data sources. The elimination process for data source review will involve a two-stage process, with **Stage One** being a determination as to which data sources are needed or even useful to the monitoring tool.

The following table will form part of the elimination process for data sources. The data sources have been reviewed and categorized based on utility to and limitations of the proposed monitoring process (Goldman et al, 1992; Holzner et al, 1993; Thacker et al, 1996; Health Canada, 1999; CDC, 2000). Data sets that are not useful to the monitoring process at this time will be eliminated i.e., the sources were not needed to inform the indicator set. (As the data sets were reviewed, it was important to keep in mind that the indicator sets required two types of information: data for national and provincial comparisons, along with regional and community data in order to evaluate effective program and service delivery.)

Table 6.3 Selected Data Sources Relevant to Labrador Inuit, Limitations of Data and First-Step Elimination Process

Code: I = Incomplete data; L = limited time frame; N = useful at national, provincial or regional level only; NN = not needed to inform indicator set at this time; Q = poor data quality; R = not representative; T = Not timely

Title of Data Source	Scope	Responsible Organizations	Information is available from	Dates	Limita-tions of Data	Data Source Eliminated (E) or Not Eliminated (NE)
NIHB Patient Statistics	Regional	Labrador Inuit Health Comm. (LIHC)	Client referrals	1991 to present	N	NE
Public Health Death Books	Community - Regional	LIHC	Death certificates	1997 to present	L	NE
Public Health Birth Books	Community - Regional	LIHC	Live Birth Notification Forms (LBNF)	1997 to present	L	NE
Community Profiles	Regional	LIHC	Community agencies	1997 to present	L	NE
Addictions Treatment Center Client Database	Regional	LIHC	Client admission forms	1987 to present	N, NN	E
Mental Health Databases	Regional	LIHC	Client interface and referrals	1993 to present	I, T	NE
Labrador Inuit Regional Health Survey	Regional	LIHC	Population survey respondents	1997 (likely to become longitudinal)	L	NE
Post Secondary Student Support Program	Regional and Provincial	Labrador Inuit Association (LIA)	Student applications		N	NE
Employment Support Services	Regional	Torngait Services Incorporated (TSI)	Client work applications	1995- 1999	I, N, NN, Q, T	E
Training and Education Database	Regional	Labrador Inuit Association (LIA)	Client resumes	1995-1999	I, N, Q, T	NE
LIA Membership List	Regional	Labrador Inuit Association (LIA)	Membership applications	1985-present	Q, T	NE
Young Offenders Information System (YOIS)	Provincial and Regional	Department of Health and Community Services	Community referral information		NN	E
Child Welfare Information System	Provincial and Regional	Department of Health and Community Services	Community referral information		NN	E
Child Care Population	Provincial and	Department of Health &	Child Care Manager's		NN	E

Movement	Regional	Community Ser.	Reports			
Group Home Population Movement	Provincial and Regional	Department of Health and Community Services	Group Home Coordinator's Reports		NN	E
Communicable Disease Control (CDC)	Provincial	Department of Health and Community Services	Health Care provider and laboratory notification	1954 to present		NE
Immunization Database	Provincial	Department of Health and Community Services	Immunization cards	1954 to present		NE
Immunization Database	Regional	Health Labrador Corporation (HLC)	Client immunization consent forms	1995 to present		NE
Tuberculosis (TB) Database	Regional	HLC, LIHC, and Sheshatshiu Health Comm	Health care providers referral forms	1954 to present	I, Q	NE
Tuberculosis Registry	Provincial	Department of Health and Community Services	Client referral form	1990 - present	I	NE
Client Referral and Management System (CRMS)	Provincial	Department of Health and Community Services	Client interaction with the system	Currently on hold for Labrador region	NN	E
Hard copy records of clinic and home visits	Regional	Health Labrador Corporation (HLC)	Community clinic and hospital registries	Intermitte-ntly from the 1950's to present	I, Q, T	NE
Hard copy records of hospital emergency visits, laboratory and radiology utilization	Regional	Health Labrador Corporation (HLC)	Community clinic and hospital registries	Intermitte-ntly from the 1950's present	I, Q, T	NE
Breast-feeding database (LoPHID)	Partially Regional	Health Labrador Corporation (HLC)	Live birth notification forms (LBNF) supplemented by a breast feeding survey	1998	I, R	NE
Clinical Database Management System (CDMS)	Provincial	Health Labrador Corporation (HLC) Addictions Services	Client demographic profile sheet		NN	E
Provincial Perinatal Database	Provincial	Newfoundland and Labrador Provincial Perinatal	Infant referral forms	In the development -al stages at present	NN	E

		Committee				
Work Injuries Database	Provincial	Occupational Health and Safety Division, Department of Employment and Labor Relations	Completed Workplace Health and Safety Compensation Commission forms			NE
Community Health Nursing Information System (CHNIS)	Provincial	Department of Health and Community Services	Community Nursing reports	1980's to present	I, NN, T	E
Integrated Support Services Program (ISSP) Child/Youth Profile	Provincial with regional focus	Departments of Health and Community Service, Education and Justice	Care providers at the community level	1999 to present	I, L, NN	E
MCP	Provincial	Newfoundland and Labrador Medical Care Commission	Client application forms	1969 to present	NN	E
Police Information Retrieval System (PIRS)	National and provincial	Royal Canadian Mounted Police (RCMP)	Client files upon interaction with the system			NE
Canadian Police Information Center (CPIC)	National	Royal Canadian Mounted Police (RCMP)	Client files upon interaction with the system		NN	E
Simplified Paperless Universal Reporting System (SPURS)	Community -Regional, can be linked to National	Royal Canadian Mounted Police (RCMP)	Client files upon interaction with the system			NE
Provincial Court Records	Regional	Labrador Legal Services (LLS)	Court worker referrals	1981-1995	NN	E
Provincial Court Information System	Provincial	Department of Justice	Client referrals		NN	E
Community Corrections Information System	Provincial	Community Corrections, Department of Justice	Conditional release referrals		NN	E
Sentence Administration Information System	Provincial	Adult Corrections, Department of Justice	Sentence reports		NN	E
Crown Attorney Case Management System	Provincial	Criminal Law Division, Department of Justice	Criminal investigation data		NN	E
Population Demographics	National	Statistics Canada	Population survey respondents	1991, 1996, 2001 (every		NE

(Aboriginal Peoples Survey – APS, Census Canada)				five years)		
Community Workload Increase System (CWIS)	National	Medical Services Branch (MSB), Health Canada	Aboriginal organizations provide community information		I, L, NN, T	E
Health Information System (HIS)	National	Medical Services Branch (MSB), Health Canada	Aboriginal organizations will input client information from interactions	Not currently rolled-out to Labrador	NN	E
National Health Surveillance Infostructure (NHSI)	National	Health Canada		Currently in the develop-mental stages	NN	E
Provincial and national health related reports	National	Canadian Institute for Health Information (CIHI)	Participating health care organizations	1969 to present		NE
Baptismal Records	Community and Regional	Moravian Church in Labrador	Personal communication with families	1700s to present	NN	E
Persons Joined in Holy Matrimony	Community and Regional	Moravian Church in Labrador	Personal communication with applicants	1700s to present		NE
Persons Departed this Life	Community and Regional	Moravian Church in Labrador	Previous church records, personal communication with families, personal communication with health care providers	1700s to present		NE
Cancer Registry	Provincial	Newfoundland Cancer Treatment and Research Foundation	Health care referrals and referral agencies	1969 to present		NE
Student Information	Community - Regional	Labrador School Board	Community Schools	1950's to present		NE
High School Transcript Information System	Provincial	Provincial Department of Education, Research, Statistics and Planning Division	Community Schools and Board offices			NE
Student Withdrawal Information System	Provincial	Provincial Department of Education, Research,	Community Schools and Board offices		NN	E

		Statistics and Planning Division				
Provincial and regional health related reports	Provincial	Newfoundland and Labrador Center for Health Information (NLCHI)	CDMS information, CIHI and other health related sources			NE
Administrative System (Taxation listing and municipal enumeration)	Regional and community	Labrador Municipal Councils	Interaction with community members			NE
Births, deaths and marriages	Provincial	Vital Statistics Division, Department of Government Services and Lands	Live Birth Notification Form, Birth Certificate, parental application, Marriage Certificate, Death Certificate	1960's to present		NE

Code: I = Incomplete data; L = limited time frame; N = useful at national, provincial or regional level only; NN = not needed to inform indicator set at this time; Q = poor data quality; R = not representative; T = Not timely

6.3.1 **Results of the First Step in the Elimination Process**

The elimination process, using the criteria outlined, weeded out a number of data sources that were not necessary for use with the health status monitoring system at this time. Of the fifty-three (53) data sources reviewed, twenty-three (23) or 43% were eliminated with thirty (30) or 57% remaining after the first step. The number of data sources and those screened in and out of the process at this point are outlined in the following table.

Table 6.3.1.**Data Sources Eliminated and Remaining From the First Step of the Elimination Process**

Type of Data Source	**Total Number**	**Eliminated (%)**	**Remaining (%)**
Labrador Inuit	11	2 (18%)	9 (82%)
Provincial	29	16 (55%)	13 (45%)
Federally based	5	3 (60%)	2 (40%)
Community	4	1 (25%)	3 (75%)

level			
Municipal Council	1	0 (0%)	1 (100%)
Policing	3	1 (33%)	2 (67%)
Totals	**53 (100%)**	**23 (43%)**	**30 (57%)**

Labrador Inuit Data Sources: Two (2) or 18% of these eleven (11) local, easily accessible, relatively inexpensive data sources were eliminated. The Employment Support Services database and the Training and Education data source are generally equivalent, but the Training and Education database is considered to be more up to date and more resourced. The Employment Support Services database was therefore eliminated. The Addictions Treatment Center Client Database did not contain necessary data to inform the indicator set.

The majority of these sources were developed specifically for program and service review, and although there are some challenges (i.e. system problems, staffing related issues, etc), are seen as workable and usable. As well, the systems which have a limited amount of data will acquire a greater volume with time. It is also expected that the Labrador Inuit Regional Health Survey (LIRHS) will become longitudinal, thus providing information about a cohort over a number of years.

Provincial Databases: Sixteen (16) or 55% of the twenty-nine (29) possible data sources were eliminated.

Two (2) of the provincial systems, the Client Referral and Management System (CRMS) and the Provincial Perinatal Database, were eliminated because one (CRMS) was currently on hold for roll-out in Labrador, while the other was in the developmental stages. Nine (9) provincial systems were eliminated in this first round (i.e. Child Care Population Movement, Group Home Population Movement, Community Health Nursing Information System, Integrated Support Services Database, Young Offenders Information System, Child Welfare Information System, MCP, Clinical Database Management

System and the Student Withdrawal Information System). These systems are not necessary as the chosen indicators do not require the types of data they provide. These sources can be put on hold for use once the indicator set is further developed and refined.

Five (5) systems, the Sentence Administration Information System, Crown Attorney Case Management System, Provincial Court Records, Provincial Court Information System, and Community Corrections Information System were eliminated because the information in these systems is not available for public use.

Thirteen (13) or 45% of the twenty-nine (29) possible data sources were not eliminated. As a foundation for the monitoring system, these sources were generally seen as:

- generally useful, as they are often the only source of information;
- somewhat accessible;
- not too costly;
- relatively good quality data;
- a number of systems containing a great deal of information, spread over a great deal of time;
- difficult to utilize when attempting to break-out data for the region; but
- useful when preparing general regional and provincial comparisons.

The Newfoundland Center for Health Information (NLCHI) was screened into the process as this agency can provide reports and data both regionally and provincially upon request. These types of reports are useful when preparing background information and documents from the proposed system. As well, reports such as these would be useful for regional comparisons.

Federal Systems: Three (3) or 60% of the five (5) possible Federal health related databases were eliminated during this round. For example, the information contained in the Community Workload Increase System (CWIS) actually comes from data collected at the local level through Community Profiles, Birth Books, Death Books,

etc. Our organization already has access to this information through more direct methods – not eliminating this database would result in unnecessary duplication.
The Health Information System (HIS), which will be an extremely useful system if accepted by our organization, is still in the investigative stages in the region. Many of the components within the system could be useful to the proposed tool with time, but the system is currently very much individualized and not necessarily population based. It has been eliminated for the time being.

The National Health Surveillance Infostructure (NHSI) was eliminated as it is in the developmental stages.

The Canadian Center for Health Information (CIHI) was screened into the process as this agency can provide a wealth of administrative information from its seven (7) databases to inform the proposed system. There is a cost involved in receiving this information and the applicant must pay to be a subscriber to the system. The cost is a limitation to access but is currently unavoidable.

Community Systems: The Moravian Church Baptismal Records (1 or 25% of a possible 4 community databases), while containing an enormous amount of information (and essentially complete for Labrador Inuit as it contains information on all children baptized in the Moravian Church in the community), were eliminated, as this information is not currently required. Information regarding births can be obtained from community level Birth Books. To include the Baptismal Records as a potential data source would be a duplication of information (though this holding was coming at the topic of "births" from a different perspective).

Municipal Council data were not eliminated, as its holdings would further add to community demographics complied through the Labrador Inuit Association (LIA) Membership List. The LIA listing does not contain community members, but rather all

members of LIA. A comprehensive health indicator set would need information on all regional constituents.

Policing data Holdings: One (1) or 33% of three (3) policing databases, the Canadian Police Information Center (CPIC) was eliminated as it is generally national in nature and linked to Motor Vehicle Registrations – not necessarily the most efficient means of tracking individuals within the region of concern. The Police Information Retrieval System (PIRS) and the Simplified Paperless Universal Reporting System (SPURS) were not eliminated as local, regional and provincial data is available from both systems.

6.4 **Rating the Remaining Data Sources**

The next step in the two-stage elimination process for the data inventory was to rate the remaining data sources on two particular areas – that of **Data Quality** and **Practicality** (Thacker et al, 1996; CDC, 2000; Holzner et al, 1993; Goldman, 1992, Health Canada, 1999). A Likert rating scale was utilized. Based on information obtained from a review of the data sources, each remaining data source was rated in both category areas and given a rating number. These numbers were then entered into a rating chart. Where the data source was the only available information source, it would either have to be used no matter what the score or some other means of obtaining the data would have to be suggested (i.e. the development of an additional information gathering system). Where there are a number of sources of data, it was expected that the source with the highest score would be used as its components had the better rating.

6.4.1 **Data Quality Rating Scales**

The following are Likert data quality scales used to rate the thirty (30) databases not eliminated in the first stage of the elimination process. These rating scales were developed based on data quality criteria emerging from the reviewed literature (Thacker

et al, 1996; Goldman et al, Holzner et al, 1993; 1992; CDC, 2000; Health Canada, 1999). The ratings were assigned by the researcher based on knowledge of and research into the various data sources and from information gathered through Key Informant Interviews.

Timely (are the data updated on a regular basis i.e. weekly, monthly):

1	2	3	4	5
Not updated	Seldom updated	Sometimes updated	Frequently updated	Regularly updated

Complete (are all data categories present and available):

1	2	3	4	5
Not complete	Seldom complete	Sometimes complete	Frequently complete	Very complete

Support system (is a system in place to support database i.e. resources, input staff, etc.):

1	2	3	4	5
No support system in place	Seldom in place	Sometimes in place	Frequently in place	Support system consistently in place

Reliability (can the data be replicated):

1	2	3	4	5
Not reliable	Seldom reliable	Sometimes reliable	Frequently reliable	Very reliable

Ease of usage (refers to both its structure and ease of operation; is the system as simple as possible while still meetings its objectives)

1	2	3	4	5
Not at all easy to use	Seldom easy to use	Sometimes easy to use	Frequently easy to use	System is easy to use

Flexibility (can the system adapt to changing information needs or operating conditions with little additional cost in time, personnel, or allocated funds):

1	2	3	4	5
Not at all flexible	Seldom flexible	Sometimes flexible	Frequently flexible	Data is very flexible

Acceptability (are individuals and organizations willing to participate in the surveillance system):

1	2	3	4	5
Not at all acceptable	Seldom acceptable	Sometimes acceptable	Frequently acceptable	System is very acceptable

Table 6.4.1 **Rating the Data Sources by Data Quality Criteria**

	Data Quality							
Title of data source	**Timely**	**Com-plete**	**Sup-port system**	**Reliable**	**Ease of usage**	**Flex-ibility**	**Accept-ability**	**Rating Score**
NIHB Statistics	5	5	5	4	4	4	4	31/35
Public Health Death Books	5	5	5	5	5	5	5	35/35
Public Health Birth Books	5	5	5	5	5	5	5	35/35
Community Profiles	4	3	4	4	4	3	3	25/35
Mental Health Databases	3	3	3	3	4	3	3	22/35
Labrador Inuit Regional Health S.	1	5	4	4	4	1	4	23/35
LIA Post Secon-dary Student Support Program	4	4	3	4	4	4	4	27/35
Training and Educa-tion database	3	3	3	3	4	3	4	23/35
LIA Member-ship list	3	3	4	3	4	3	3	23/35
Communi-cable Disease Control	5	4	5	5	5	5	5	34/35
Prov. Immuni-zation Data	3	3	4	4	4	5	5	27/35
Regional Immuni-zation Database	4	4	3	4	4	4	4	27/35
Regional TB Database	3	3	3	4	4	4	2	23/35
Prov. TB Registry	3	3	3	4	4	4	4	25/35

Title of data source	Timely	Com-plete	Sup-port system	Reliable	Ease of usage	Flex-ibility	Accept-ability	Rating Score
Hard copy records of clinic and home visits	4	4	2	4	4	4	3	25/35
Hard copy records of hospital emergency visits, laboratory, radiology utilization	3	4	2	4	4	4	3	24/35
Breast feeding database	1	1	2	3	4	4	3	18/35
Work Injuries Database	3	3	3	4	4	4	3	24/35
Police Information Retrieval System	5	4	5	4	4	4	4	30/35
Simplified Paperless Universal Rep. Sys.	5	4	5	4	4	4	4	30/35
Population Demograph -ics (Stats Canada)	4	4	4	4	3	3	3	25/35
Persons joined in Holy Matrimony	5	5	5	5	5	5	5	35/35
Departed Persons Database	5	5	5	5	5	5	5	35/35
National and provincial health related reports (CIHI)	4	4	4	3	4	3	3	25/35
Cancer Registry	4	3	3	3	4	3	3	23/35
Student Information	4	3	4	4	4	3	3	21/35

Title of data source	Timely	Com-plete	Sup-port system	Reliable	Ease of usage	Flex-ibility	Accept-ability	Rating Score
High School Transcript Information System	4	3	4	4	4	4	4	27/35
Provincial and regional health related reports (NLCHI)	4	4	4	3	4	3	3	25/35
Taxation listing and municipal enumera-tion	3	3	4	4	4	4	4	26/35
Births, deaths and marriages (Vital Statistics)	4	3	4	3	4	3	3	24/35

6.4.2 **Data Quality Rating Results**

A review of the ratings for data quality criteria will be undertaken by category, as was done with the first step of the process. There were seven rating criteria for each database, with five steps on the rating scale, yielding a possible high score of 35/35 (100%).

Labrador Inuit Databases: All nine (9) databases scored between 22/35 and 35/35, with the Public Health Birth and Death Books scoring highest (35/35 – 100%) and the Mental Health database scoring 22/35 (63%). The Public Health Birth and Death Books are kept in hard copy format and are kept current on a consistent basis, possibly due to the monthly reporting requirements and the simplicity of the process. The Mental Health databases are not kept as current as they could be due to staffing and time constraints. There is not always a support system in place to update and review the information. There are also problems with the platform housing the data – thought is

being given to transporting the information into a more user friendly and responsive electronic system.

The NIHB program (which scored 31/35 or 89%) has a requirement to report to the Federal government on a quarterly basis and the system must be kept current as client interface with this program is constant, hence the reason for the higher score. It should be noted that health related information about non-LIA members living in coastal communities is not included in the NIHB database; another source for this information is required.

The Labrador Inuit Regional Health Survey (LIRHS), LIA's Training and Education database, and the LIA Membership List all scored 23/35 (66%). The LIRHS, while an excellent source of self-reported health status, was merely one snapshot in time (spring 1997), hence the data are not current. As well, the survey tool is not a flexible tool once developed – so it and the process lacked flexibility once delivered. These two criteria were scored low, resulting in a lower rating score. The two other systems generally scored lower in all categories.

Community Profiles scored 25/35 (71%) for data quality. The Post Secondary Student Support Program (PSSSP) database scored 27/35 (77%). The PSSSP program experiences considerable client interaction and also has an upward reporting requirement to the funding agency.

Provincial Systems: The thirteen (13) databases available through the provincial system all scored between 18/35 and 34/35, with the Breast-feeding database scoring 18/35 (51%) and the Communicable Disease Control (CDC) database scoring 34/35 (97%). The Breast-feeding database scored low in areas of regular updating (as it was a one time snapshot), on completeness (it did not include comprehensive information on the region of concern), and on support system, as the region will not be able to

maintain this system once the current research project ends. It did score relatively well in the other areas. The CDC database scored consistently well in all areas due to the nature of the system, its weekly updating requirement by targeted staff and the general ease of reporting once system usage is understood.

Eight (8) of the 14 databases scored between 23/35 (66%) and 26/35 (74%). Three (3) databases scored 27/35 (77%) – the Provincial Immunization database, the Regional Immunization Database and the High School Transcript Information System.

Federal Systems: The two health related Federal systems, that of Population Demographics (Statistics Canada, Census) and the Canadian Institute for Health Information (CIHI), both scored 25/35 (71%). Both these system scored well in four categories, with the areas of simplicity, flexibility and acceptability being the exception.

Community Systems: The two community level databases, maintained by the Moravian Church in Labrador, both scored 35/35 (100%). Both these information sources are updated regularly, are complete, have a support system in place (community church Elders), can be easily replicated, are very simple in their hard copy format, and are flexible and acceptable to all involved with the systems.

The Student Information database, maintained by community schools, scored 21/35 (60%).

Policing data Holdings: The two remaining policing databases, Simplified Paperless Universal Reporting System (SPURS) and Police Information Retrieval System (PIRS), both scored 30/35 (86%).

Municipal Councils: The Municipal Council system rated 26/35 or 74%. This system scored well in all areas except that of timeliness and completeness because the system is only updated once per year.

6.4.3 **Data Practicality Rating Scales**

The following are Likert data practicality scales used to further rate the same thirty (30) databases which had not been eliminated in the first stage of the elimination process. These rating scales were developed based on emerging data practicality criteria from the reviewed literature (Thacker et al, 1996; Goldman et al, 1992; CDC, 2000; Health Canada, 1999). The ratings were assigned by the researcher based on knowledge of and research into the various data sources and from information gathered through Key Informant Interviews.

Accessibility (can the data be readily shared; is it user-friendly):

1	2	3	4	5
Not accessible	Seldom accessible	Sometimes accessible	Frequently accessible	Readily accessible

Cost (is the database costly to develop, maintain, and share):

1	2	3	4	5
Expensive	Greater than Average cost	Average cost	Some cost	No cost

Ethical (does not breach confidentiality, protects client identification, does not allow for communities to be identified, does not allow community members in small communities to be identified):

1	2	3	4	5
Not ethical	Seldom ethical	Sometimes ethical	Frequently ethical	Highly ethical

Denominator information is available:

1	2	3	4	5
Not available	Seldom available	Sometimes available	Frequently available	Denominator is available

Unique identifier (is a unique identifier utilized):

1	2	3	4	5
Not utilized	Seldom Used	Sometimes Used	Frequently Used	Always Used

Format (is the data available in a usable format i.e. electronic, hard copy, platform compatibility, etc):

1	2	3	4	5
No Format	Seldom formatted	Sometimes formatted	Frequently formatted	Always formatted

Archives (is the data retained in readily accessible archival form):

1	2	3	4	5
No archives	Seldom Archived	Sometimes Archived	Frequently Archived	Always Archived

Table 6.4.3 **Rating of Data Sources by Data Practicality Criteria**

	Practicality							
Agency	**Access-ability**	**Cost**	**Ethical**	**Denomi-nator info available**	**Unique identifier**	**Format**	**Archives**	**Rating Score**
NIHB Patient Statistics	4	4	4	4	5	5	5	31/35
Public Health Death Books	5	5	5	5	1	5	5	31/35
Public Health Birth Books	5	5	5	5	1	5	5	31/35
Community Profiles	5	4	4	5	1	5	5	29/35
Mental Health Databases	3	4	4	2	5	4	4	26/35
Labrador Inuit Regional Health Survey	5	4	5	5	1	5	5	30/35
Post Secondary Student Support Program	4	4	4	5	5	4	4	30/35

Agency	Access-ability	Cost	Ethical	Denomi-nator info available	Unique identifier	Format	Archives	Rating Score
Training and Education database	3	4	4	5	5	4	5	30/35
LIA Member-ship list	3	4	4	5	5	4	4	29/35
Comm. Disease Control	4	5	5	5	5	5	5	34/35
Provin-cial Immuniza tion Data-base	3	4	5	5	1	4	4	26/35
Regional Immun. Database	3	4	5	5	1	4	4	26/35
Regional TB Data	3	3	5	5	4	4	4	28/35
Provincial TB Registry	3	4	5	5	1	4	4	26/35
Hard copy records of clinic and home visits	3	4	3	2	5	3	3	23/35
Hard copy records of hospital emergenc y visits, laboratory radiology utilization	3	4	3	2	5	3	3	23/35
Breast feeding database	3	4	4	4	5	3	3	26/35
Work Injuries	3	4	4	4	5	4	4	28/35
Police Informa-tion Retrieval System (PIRS)	4	5	5	5	5	5	5	34/35

Agency	Access-ability	Cost	Ethical	Denomi-nator info available	Unique identifier	Format	Archives	Rating Score
Simpli-fied paperless SPURS Reporting	4	5	5	5	5	5	5	34/35
Pop.Dem-ographics Stats Can	5	2	5	4	1	5	5	27/35
Persons joined in Holy Matri-mony	5	5	5	5	1	5	5	31/35
Departed Persons	5	5	5	5	1	5	5	31/35
National and provincial health related reports	5	3	5	5	5	4	5	32/35
Cancer Registry	4	5	5	5	5	4	5	33/35
Student Informa-tion	4	5	5	5	5	4	5	33/35
High School Trans.info	4	5	5	5	5	4	5	33/35
Provincial regional health reports NLCHI	5	5	5	5	5	4	5	34/35
Taxation listing and municipal enumerati on	4	5	5	5	1	5	5	30/35
Births, deaths and marriages (Vital Statistics)	3	4	4	5	5	4	5	30/35

6.4.4 **Data Practicality Rating Results**

A review of the ratings for data practicality criteria will be undertaken by category, as was done with the first step of the process. There were seven rating criteria for each database, with five steps on the rating scale, yielding a possible high score of 35/35 (100%).

Labrador Inuit Databases: These nine (9) databases scored between 26/35 (74%) and 31/35 (86%) on the data practicality criteria. The Non Insured Health Benefits (NIHB) database and the Public Health Birth and Death Books scored 31/35 (89%). Both the Birth and Death Books use client names rather than a unique identifier when collecting data, hence the lower rating in this category. The Mental Health database scored 26/35 (74%). This system scored poorly on accessibility and availability of denominator information.

Three (3) of these sources, the Labrador Inuit Regional Health Survey (LIRHS), Post Secondary Student Support Program (PSSSP) database, and LIA Training and Education database all scored 30/35 (86%). While two others, Community Profiles and LIA Membership List scored 29/35 (83%). The Community Profiles do not use a unique identifier, rather data is gathered about each community in aggregate format.

Provincial Systems: All thirteen (13) of these systems scored between 34/35 and 23/35. The Communicable Disease Control (CDC) database and the Newfoundland Center for Health Information (NLCHI) databases both scored 34/35 (97%), while both sets of hard copy records – Clinic and Home visits, and Hospital Emergency Visits, Laboratory and Radiology Utilization both scored 23/35 (66%). These two hard copy systems scored poorly in the denominator availability category.

Two (2) databases, the Cancer Registry, and High School Transcript Information System each scored 33/35 (94 %). Vital Statistics - Births, Deaths and Marriages scored 30/35 (86%). This database scored less than optimally in the accessibility category as compared to the locally available databases.

Two (2) databases, the Regional TB database and Work Injuries database scored 28/35 (80%). Both of these databases scored lower in the accessibility category. The Provincial Immunization database, the Regional Immunization database, the Breast-feeding database and the Provincial TB Registry scored 26/35 (74%). Three of these systems do not use a unique identifier, hence the lower score. The Breast-feeding database scored lower in the categories of accessibility, format and archives as information is only available on a one-time basis.

Federal Systems: The Canadian Institute for Health Information (CIHI) received a rating score of 32/35 (91%), while Statistics Canada databases received a score of 27/35 (77%). Statistics Canada does not use a unique identifier, rather data are gathered in aggregate format, hence the lower score. As well, information from this agency is quite costly.

Community level Systems: Databases maintained by the Moravian Church in Labrador, Persons Departed this Life and Persons Joined in Holy Matrimony, both received a score of 31/35 (89%). These systems are both client based and do not use a unique identifier.

The community-based Student Information system scored highly at 33/35 (94.29%).

Policing data Holdings: Both policing databases, Simplified Paperless Universal Reporting System (SPURS) and Police Information Retrieval System (PIRS), received a rating of 34/35 (97%).

Municipal Councils: The Municipal Council system rated 30/35 or 86%. This system rated well in all areas except accessibility due to its annual updating.

6.5 Overview of Rating Results

The study inventory uncovered fifty-three (53) potential data sources that could be used to inform the chosen indicator set. Of these fifty-three (53), twenty-three (23) were eliminated in the first round, five (5) because their contents could not be shared, while eighteen (18) others did not contain information useful to the model at this time. The next step in the elimination process rated the thirty (30) remaining sources as to data quality and data practicality.

The nine (9) Labrador Inuit databases rated scored relatively well in data quality (rating between 22/35 [63%] and 35/35 [100%]). The thirteen (13) provincial data sources did not score quite as well in data quality (rating between 18/35 [51%] and 34/35 [97%]). Both Federal systems scored relatively well in data quality (25/35 or 71%). Two (2) of the three (3) community systems scored (35/35) 100%, while the other scored 21/35 (60%). The two policing data sources both scored well at 34/35 or 97%. The municipal council system scored 26/35 (74%).

In the data practicality ratings the nine (9) Labrador Inuit databases scored between 26/35 (74%) and 31/35 (89%). The thirteen (13) provincial sources scored between 23/35 (66%) and 34/35 (97%). One (1) of the two (2) Federal systems received a score of 32/35 (91%) while the other scored 27/35 or 77%. Two (2) of the three (3) community level systems scored 31/35 (89%), with the other scoring 33/35 or 94 %. The two (2) policing systems scored well at 34/35 (97 %). The municipal council system scored 30/35 (86%) in data practicality.

When reviewing rating scores of data quality, low scoring of data sources (i.e. < 3) was attributed to lack of timeliness (2), lack of completeness (1), an inconsistent support

system (3), a lack of flexibility (1) and a lack of acceptability (1). When reviewing the scoring for data practicality, low scoring of data sources (i.e. < 3) was attributed to high cost of data (1), lack of denominator information (3) and the lack of a unique identifier (11).

6.6 **Matching Indicators to Data Sources**

These two rating processes yielded a total of thirty (30) data sources that could potentially inform the chosen indicator set. The next step in the process was a determination as to the best source of information to inform the chosen model (please see **Appendix C**), based on rating score, as a number of sources contained similar or comparable information.

6.6.1 **Mortality Information**

Mortality information was available through four (4) sources, which received scores in both rating areas as outlined in **Table 6.6.1**. It should be noted that these information sources scored well overall, with an average score of 29.75/35 (85%) for both data quality and data practicality.

Table 6.6 1 **Total Rating Scores of Mortality Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Public Health Death Books	35/35 (100%)	31/35 (89%)	66/70 (94%)
Persons Departed this Life (Moravian Mission)	35/35 (100%)	31/35 (89%)	66/70 (94%)
Provincial Births, Deaths and Marriages (Vital Statistics)	24/35 (69%)	30/35 (86%)	54/70 (77%)
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Average Rating	29.75/35 (85%)	29.75/35 (85%)	59.5/70 (85%)

The Public Health Death Books and the Moravian Mission Departed this Life records have received equal ratings in both areas (with a total score of 66/70 or 94%). But Public Health Death Books are held in each coastal community, whereas the Moravian Mission records are not held in two Labrador Inuit communities. As well, the Moravian Death records, while fully complete for Labrador Inuit who are buried in the community, do not contain information for who non-Inuit might have died in the community but were buried elsewhere.

The provincial Vital Statistics (with a total score of 54/70 or 77%) contains information on Labrador, which should be available by community. This information is not as accessible or as timely as the local data source. But, our health care organization should be aware that while all mortality information flows from the death certificate, these documents are forwarded to Vital Statistics for coding and entering into the provincial system. The coding could result in a differentiation of the cause of death – primary and secondary - and might be somewhat dissimilar from the information surfacing at the community level at the time of death.

Statistics Canada (with a total score of 52/70 or 74%), while an excellent mortality information source, does not rate as highly in the areas of cost, accessibility, and unique identifier availability.

For the purpose of informing the indicator set at the community level, the Public Health Death Books appears to be the best information source for detailed numbers and immediate cause of death.

6.6.2 **Birth Information Sources**

Birth information was available through three (3) sources, which received scores in both rating areas as outlined in **Table 6.6.2**. It should be noted that these information sources

scored well overall, with an average score of 28/35 (80%) for data quality and 29.33/35 (83%) for data practicality.

Table 6.6.2 **Total Rating Scores of Birth Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Birth Books	35/35 (100%)	31/35 (89%)	66/70 (94%)
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Provincial Births, Deaths and Marriages (Vital Statistics)	24/35 (69%)	30/35 (86%)	54/70 (77%)
Average Score	28/35 (80%)	29.33/35 (83%)	57.33/70 (82%)

The Public Health Birth Books received the highest score in both rating areas, with a total score of 66/70 or 94%. These hard copy records are held in all coastal communities and are readily accessible. The books do not contain a personal identifier for the individual client and thus the reduction in score in the data practicality area.

The provincial Vital Statistics (with a total score of 54/70 or 77%) contains information on Labrador, which should be available by community. This information is not as accessible or as timely as the local data source. Canadian Vital Statistics (with a total score of 52/70 or 74 %) receives its information from the province in aggregate format. The source of all information is the Live Birth Notification Form (LBNF) usually completed at the community or regional level post delivery.

The Public Health Birth Books would seem to be the best sources of data at the community level, based on the results of the rating criteria.

6.6.3 **Health Condition Information Sources**

Health condition information was available through six (6) sources, which received scores in both rating areas as outlined in **Table 6.6.3**. It should be noted that these

information sources received an average score of 26/35 (74%) for data quality and 30/35 (86%) for data practicality.

Table 6.6.3 **Total Rating Scores of Health Condition Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Community Profiles	25/35 (71%)	29/35 (83%)	54/70 (77%)
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit Regional Health Survey (LIRHS)	23/35 (66%)	30/35 (86%)	53/70 (76%)
Provincial Communicable Disease Control Database	34/35 (97%)	34/35 (97%)	68/70 (97%)
Provincial Work Injuries Database	24/35 (69%)	28/35 (80%)	52/70 (74%)
Canadian Institute for Health Information (CIHI), Hospitality Mortality Database	25/35 (71%)	32/35 (91%)	57/70 (81%)
Average Score	26/35 (74%)	30/35 (86%)	56/70 (80%)

Unfortunately this indicator section cannot be solely informed by one information source, as neither is comprehensive enough to include the entire category.

The first six (6) indicators in this section, related to overweight, arthritis, diabetes, asthma, chronic pain and depression can receive information from three (3) inventory sources: Community Profiles (with a total score of 54/70 or 77%), the Labrador Inuit Regional Health Survey (LIRHS) (with a total score of 53/70 or 76%) and Statistics Canada (with a total score of 52/70 or 74%).

Community profiles are completed on an annual basis. These documents are compiled in conjunction with community agencies and yield the most up-to-date source of information on that community at the time of collection. These tools are useful for

comparison purposes from year to year – for inter community and regional purposes. Data from the APS and other national surveys does not provide enough information when assessing health status for decision making at the community and regional level. Under APS, sampling numbers are small per group and the tool is intended for use nationally, rather than at the community or regional level. The community level data source, with the highest score, would appear to be the best option when the information required is available as it is more readily accessible, flexible, simplistic and much less costly.

The next indicator in this section seeks data on injury hospitalization and can be informed by two (2) sources from the data inventory: CIHI (with a total score of 57/70 or 81%) and the provincial Work Injuries Database (with a total score of 52/70 or 74%). Although the provincial source has the lower rating score, this source is seen as most preferable as it is more easily accessible, less costly and would yield more regional detail.

The final indicator in this section looks at the topic of food and waterborne diseases and can only be informed by the provincial Communicable Disease Control Database, with a total score of 68/70 or 87%.

6.6.4 **Activity Limitation and Well-Being Information Sources**

Activity limitation and Well-being information was available through two (2) sources, which received scores in both rating areas as outlined in **Table 6.6.4**. It should be noted that these information sources received an average score of 24/35 (69%) for data quality and 28.5/35 (81%) for data practicality.

Table 6.6.4 **Total Rating Scores of Activity Limitation and Well-Being Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit	23/35 (66%)	30/35 (86%)	53/70 (76%)

Regional Health Survey (LIRHS)			
Average Score	24/35 (69%)	28.5/35 (81%)	52.5/70 (75%)

The two information sources for this section both scored relatively closely; the LIRHS (with a total score of 53/70 or 76%) scored higher in practicality and Statistics Canada (with a total score of 52/70 or 74%) scored higher in data quality.

The LIRHS contains a great deal of information about the population of concern and with a marginally higher rating score, will be used to currently inform the seven (7) indicators in these sections on Activity Limitation and Well-being.

6.6.5 **Health Behavior Information Sources**

Health behavior information was available through four (4) sources, which received scores in both rating areas as outlined in **Table 6.6.5**. It should be noted that these information sources received an average score of 22.75/35 (65%) for data quality and 28/35 (80%) for data practicality.

Table 6.6.5 **Total Rating Scores of Health Behavior Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Community Profiles	25/35 (71%)	29/35 (83%)	54/70 (77%)
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit Regional Health Survey (LIRHS)	23/35 (66%)	30/35 (86%)	53/70 (76%)
Breast feeding database	18/35 (51%)	26/35 (74%)	44/70 (63%)
Average Score	22.75/35 (65%)	28/35 (80%)	50.75/70 (73%)

The total score for the Community Profiles was slightly better (54/70 or 77%) than that of the LIRHS (53/70 or 76%) and Statistics Canada at 52/70 or 74%. Unfortunately, the current Community Profiles would need enhancement to inform the entire Health

Behavior indicator section. But the LIRHS was formulated to be comparable to the Aboriginal Peoples Survey (APS) data and thus will inform five (5) of the six (6) indicators in this section.

The LoPHID breast feeding database, while a useful exercise for the organization of concern to mimic in future, did not score well in the data quality section (18/35 or 51%). This database is largely incomplete for the communities of concern, does not have a future support system and will not be updated on a regular basis. Thus the information from this database will not be useful to inform the sixth (6^{th}) indicator of the CIHI indicator set on breastfeeding. This indicator can be informed by the annual LIHC Community Health Profiles.

6.6.6 **Living and Working Conditions Information Sources**

Living and Working Conditions information was available through five (5) sources, which received scores in both rating areas as outlined in **Table 6.6.6**. It should be noted that these information sources received an average score of 25.6/35 (73%) for data quality and 30.8/35 (88%) for data practicality.

Table 6.6.6 **Total Rating Scores of Living and Working Conditions Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Provincial High School Transcript Information System	27/35 (77%)	33/35 (94%)	60/70 (86%)
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit Regional Health Survey (LIRHS)	23/35 (66%)	30/35 (86%)	53/70 (76%)
LIA Training and Education Database	23/35 (66%)	30/35 (86%)	53/70 (76%)
Police Information	30/35 (86%)	34/35 (97%)	64/70 (91%)

Retrieval System (PIRS)			
Average Score	25.6/35 (73%)	30.8/35 (88%)	56.4/70 (81%)

Unfortunately this indicator section cannot be solely informed by one information source, as neither is comprehensive enough to include the entire category.

Information on High School Graduation can be obtained from the provincial High School Transcript Information system, which obtained an average total score of 60/70 or 86% and from Statistics Canada, with an average total score of 52/70 or 74%. The provincial data scores consistently better in both areas and is more accessible and less costly. Thus the provincial system will be used to inform the first indicator.

The second indicator regarding post-secondary graduation can be informed by three (3) sources; Statistics Canada (with an average total score of 52/70 or 74%), the LIRHS (with an average total score of 53/70 or 76%) and the LIA Training and Education database (with an average total score of 53/70 or 76%). These three scores are all relatively close together, thus making the choosing of the source based on score a challenge. The LIA Training and Education database with a relatively good score, an ongoing support system and reasonable accessibility, would seem to be the reasonable choice for this indicator.

The next three indicators (related to employment and unemployment) can be informed by Statistics Canada (with an average total score of 52/70 or 74%) or the LIRHS (with an average total score of 53/70 or 76%). It would seem reasonable to accept the LIRHS based on higher score – especially where the data is quite accessible and less costly.

The next four indicators in this section are related to income and housing affordability. Information required for these indicators is contained only within the Statistics Canada database and is not available through locally available sources. Local data sources with this capability will need to be developed over time.

The next two indicators, related to general and youth crime rates, can be informed by Statistics Canada (with an average total score of 52/70 or 74%) or the Police Information Retrieval System (PIRS) with an average total score of 64/70 or 91%. The accessible police information system, with the higher score, will be used to inform these two indicators.

The final indicator, concerning decision latitude at work, can only receive data from Statistics Canada. Other sources do not provide the information needed for this indicator.

6.6.7 **Personal Resources Information Sources**

Personal Resources information was available through three (3) sources, which received scores in both rating areas as outlined in **Table 6.6.7**. It should be noted that these information sources received an average score of 23/35 (66%) for data quality and 30/35 (86%) for data practicality.

Table 6.6.7 **Total Rating Scores of Personal Resource Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit Regional Health Survey (LIRHS)	23/35 (66%)	30/35 (86%)	53/70 (76%)
Student Information System, Labrador School Board	21/35 (60%)	33/35 (94%)	54/70 (77%)
Average Score	23/35 (66%)	30/35 (86%)	56.4/70 (81%)

The first indicator on school readiness can receive information from two (2) sources: Statistics Canada (with a total score of 52/70 or 74%) or the Student Information System belonging to the Labrador School Board (with a total score of 54/70 or 77%). The local

and more easily accessible source has a higher rating score and will be used as the information source.

The other two indicators, looking at social support and life stress, can be informed by two sources: Statistics Canada (with a total score of 52/70 or 74%) or the Labrador Inuit Regional Health Survey (with a total score of 53/70 or 76%). Again the local source, with the marginally higher score, will be used to inform these indicators.

6.6.8 **Health System Performance (Accessibility) Information Sources**

Health System Performance (Accessibility) information was available through six (6) sources, which received scores in both rating areas as outlined in **Table 6.6.8**. It should be noted that these information sources received an average score of 26.67/35 (76%) for data quality and 27.83/35 (80%) for data practicality.

Table 6.6.8 **Total Rating Scores of Health System Performance (Accessibility) Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Regional Immunization Database, Health Labrador Corporation (HLC)	27/35 (77%)	26/35 (74%)	53/70 (76%)
Provincial Immunization Database	27/35 (77%)	26/35 (74%)	53/70 (76%)
Non-Insured Health Benefits (NIHB) Patient Statistics	31/35 (89%)	31/35 (89%)	62/70 (89%)
Newfoundland Center for Health Information (NLCHI)	25/35 (71%)	34/35 (97%)	59/70 (84%)
Community Clinic	25/35 (71%)	23/35 (66%)	48/70 (69%)

and Hospital Registries, Health Labrador Corporation (HLC)			
Average Score	26.67/35 (76%)	27.83/35 (80%)	54.5/70 (78%)

Unfortunately this indicator section cannot be solely informed by one information source, as neither is comprehensive enough to include the entire category.

The first indicator, which looks at the topic of influenza immunization for those 65 years and older, can receive information from two (2) sources: Statistics Canada (with a total score of 52/70 or 74%) or the Regional Immunization Database (with a total score of 53/70 or 76%). The local and more easily accessible data, with the marginally better score, will be used to inform the indicator.

The second indicator requires data on mammography screening and can be informed by three (3) inventory sources: Statistics Canada (with a total score of 52/70 or 74%), the Non-Insured Health Benefits (NIHB) database (with a total score of 62/70 or 89%) or the Newfoundland Center for Health Information (NLCHI), with a total score of 59/70 or 84%. The regional data source, the NIHB system, contains a great deal of information about Labrador Inuit and will be used as a source for these clientele. Information on other individuals living within the region would have to be mined from the provincial resource – NLCHI - which does not break Labrador data out by nation and should therefore supply the needed information by comparison. This indicator would therefore require two (2) data sources.

The third indicator looks at Pap Smear rates and can be informed by two (2) sources: Statistics Canada (with a total score of 52/70 or 74%) or the Community Clinic and Hospital Registries (with a total score of 48/70 or 69%). Even though the local information scores lower than the national source, it would seem to be preferable to use that more accessible and detailed information. The enhancement of these registries would be a useful future undertaking.

The fourth indicator requests information on childhood immunizations and can be informed by two (2) sources: the Regional and Provincial Immunization databases (both with an equal total score of 53/70 or 76%). The regional source will be used as it is more accessible.

6.6.9 **Health System Performance (Appropriateness) Information Sources**

Health System Performance (Appropriateness) information was available through two (2) sources, which received scores in both rating areas as outlined in **Table 6.6.9**. It should be noted that these information sources received an average score of 25/35 (71%) for data quality and 33/35 (94%) for data practicality.

Table 6.6.9 **Total Rating Scores of Health System Performance (Appropriateness) Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Newfoundland Center for Health Information (NLCHI)	25/35 (71%)	34/35 (97%)	59/70 (84%)
Canadian Institute for Health Information (CIHI), Hospital Morbidity Database	25/35 (71%)	32/35 (91%)	57/70 (81%)
Average Score	25/35 (71%)	33/35 (94%)	58/70 (83%)

The three (3) indicators in this section can be informed by two (2) information sources: the Newfoundland Center for Health Information (NLHCI), with a total score of 59/70 or 84% or the Canadian Institute for Health Information (CIHI), with a total score of 57/70 or 81%. The provincial source has the better rating score and is also linked to the national information system; it therefore seems logical to have the NLCHI inform these indicators.

6.6.10 **Health System Performance (Effectiveness) Information Sources**

Health System Performance (Effectiveness) information was available through nine (9) sources, which received scores in both rating areas as outlined in **Table 6.6.10**. It should be noted that these information sources received an average score of 26.56/35 (76%) for data quality and 30.22/35 (86%) for data practicality.

Table 6.6.10 **Total Rating Scores of Health System Performance (Effectiveness) Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit Regional Health Survey (LIRHS)	23/35 (66%)	30/35 (86%)	53/70 (76%)
Provincial Births, Deaths and Marriages (Vital Statistics)	24/35 (69%)	30/35 (86%)	54/70 (77%)
Birth Books	35/35 (100%)	31/35 (89%)	66/70 (94%)
Provincial Communicable Disease Control Database	34/35 (97%)	34/35 (97%)	68/70 (97%)
Provincial Tuberculosis Registry	25/35 (71%)	26/35 (74%)	51/70 (73%)
Regional Tuberculosis Database	23/35 (66%)	28/35 (80%)	51/70 (73%)
Newfoundland Center for Health Information (NLCHI)	25/35 (71%)	34/35 (97%)	59/70 (84. %)
Canadian Institute for Health Information (CIHI), Hospital Morbidity Database	25/35 (71%)	32/35 (91%)	57/70 (81%)
Average Score	26.56/35 (76%)	30.22/35 (86%)	56.78/70 (81%)

Unfortunately this indicator section cannot be solely informed by one information source, as neither is comprehensive enough to include the entire category.

The first indicator, on the topic of quitting smoking, could receive information from two (2) inventory sources: Statistics Canada (with a total score of 52/70 or 74%) or the Labrador Inuit Regional Health Survey (LIRHS), with a total score of 53/70 or 76%. The local, more affordable source, with the marginally higher rating score will be used to inform the indicator.

The second indicator requires data on low birth-weight and can receive information from four (4) inventory sources: Statistics Canada (with a total score of 52/70 or 74%), provincial Vital Statistics (with a total score of 54/70 or 77%), the Newfoundland Center for Health Information (NLCHI), (with a total score of 59/70 or 84%) or the local Public Health Birth Books (with a total score of 66/70 or 94%). The local source, with the higher rating score, will be used as the information source.

The next four (4) indicators, on the topics of pertussis, measles, HIV and chlamydia, can receive information from the provincial Communicable Disease Control database. This well maintained system has an excellent total score of 68/70 or 97% and can readily be used to inform these indicators.

The next indicator, which looks at Tuberculosis rates, can receive information from two (2) sources: the provincial Tuberculosis Registry or the Regional Tuberculosis database. Both these systems have an equivalent rating score of 51/70 or 73%. The local and readily accessible data source will be used.

Two (2) other indicators, pneumonia and influenza hospitalizations and ambulatory care sensitive conditions, can receive information from: the Canadian Institute for Health Information (with a total score of 57/70 or 81%) or the Newfoundland Center for Health Information (with a total score of 59/70 or 84%). The provincial source has the better

rating score and is also linked to the national CIHI information system; it therefore seems logical to have the NLCHI inform these indicators.

Statistics Canada (with a total score of 52/70 or 74%) is the only inventory source able to inform the final indicator, deaths due to medically-treatable diseases.

6.6.11 **Health System Performance (Efficiency) Information Sources**

Health System Performance (Efficiency) information was available through two (2) sources, which received scores in both rating areas as outlined in **Table 6.6.11**. It should be noted that these information sources received an average score of 25/35 (71%) for data quality and 33/35 (94%) for data practicality.

Table 6.6.11 **Total Rating Scores of Health System Performance (Efficiency) Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Newfoundland Center for Health Information (NLCHI)	25/35 (71%)	34/35 (97%)	59/70 (84%)
Canadian Institute for Health Information (CIHI), Hospital Morbidity Database	25/35 (71%)	32/35 (91%)	57/70 (81%)
Average Score	25/35 (71%)	33/35 (94%)	58/70 (83%)

The four (4) indicators of this section, on surgical day case rates, acute care inpatient sessions that may not require hospitalization, alternate level of care days, and expected compared to actual stay days, can be informed by two (2) inventory sources: the Canadian Institute for Health Information (with a total score of 57/70 or 81%) or the Newfoundland Center for Health Information (with a total score of 59/70 or 84%). The provincial source has the better rating score and is also linked to the national CIHI information system; it therefore seems logical to have the NLCHI inform these indicators.

6.6.12 **Health System Performance (Safety) Information Sources**

Health System Performance (Safety) information was available through two (2) sources, which received scores in both rating areas as outlined in **Table 6.6.12**. It should be noted that these information sources received an average score of 25/35 (71%) for data quality and 33/35 (94%) for data practicality.

Table 6.6.12 **Total Rating Scores of Health System Performance (Safety) Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Newfoundland Center for Health Information (NLCHI)	25/35 (71%)	34/35 (97%)	59/70 (84%)
Canadian Institute for Health Information (CIHI), Hospital Morbidity Database	25/35 (71%)	32/35 (91%)	57/70 (81%)
Average Score	25/35 (71%)	33/35 (94%)	58/70 (83%)

The one (1) indicator of this section, on hip fractures, can be informed by two (2) inventory sources: the Canadian Institute for Health Information (with a total score of 57/70 or 81%) or the Newfoundland Center for Health Information (with a total score of 59/70 or 84%). The provincial source has the better rating score and is also linked to the national CIHI information system; it therefore seems logical to have the NLCHI inform these indicators.

6.6.13 **Community and Health System Characteristics Information Sources**

Community and Health System Characteristics information was available through seven (7) sources, which received scores in both rating areas as outlined in **Table 6.6.13**. It should be noted that these information sources received an average score of 27.14/35 (78%) for data quality and 30.57/35 (87%) for data practicality.

Table 6.6.13 **Total Rating Scores of Community and Health System Characteristics Information Sources**

Data Source	**Data Quality Rating**	**Data Practicality Rating**	**Total Score**
Population Demographics (Statistics Canada)	25/35 (71%)	27/35 (77%)	52/70 (74%)
Labrador Inuit Association (LIA) Membership List	23/35 (66%)	29/35 (83%)	52/70 (74%)
Administrative Enumeration System, Labrador Municipal Councils	26/35 (746%)	30/35 (86%)	56/70 (80%)
Non-Insured Health Benefits (NIHB) Patient Statistics	31/35 (89%)	31/35 (89%)	62/70 (89%)
Birth Books	35/35 (100%)	31/35 (89%)	66/70 (94%)
Newfoundland Center for Health Information (NLCHI)	25/35 (71%)	34/35 (97%)	59/70 (84%)
Canadian Institute for Health Information (CIHI), Therapeutic Abortions Database, Hospital Morbidity Database, Southam Medical Database, Registered Nurses Database, National Expenditure Database	25/35 (71%)	32/35 (91%)	57/70 (81%)
Average Score	27.14/35 (78%)	30.57/35 (87%)	57.71/70 (82%)

Unfortunately this section, which contains ten (10) indicators, cannot be solely informed by one information source, as none is comprehensive enough to include the entire category.

The first indicator in this section, population count, can be informed by three (3) data sources: Statistics Canada (with a total score of 52/70 or 74%), the LIA Membership List (with a total score of 52/70 or 74%) or the Labrador Municipal Council Administrative

Enumeration System (with a total score of 56/70 or 80%). The Municipal Council system, with the higher rating, contains information about all regional constituents and is therefore the more complete and detailed system to inform the indicator.

The next indicator, teen pregnancy/ teen births, can receive information from three (3) inventory sources: the Canadian Institute for Health Information (with a total score of 57/70 or 81%), the Newfoundland Center for Health Information (with a total score of 59/70 or 84%) or the local Public Health Birth Books (with a total score of 66/70 or 94%). The local source, with the higher rating score and ease of accessibility is the logical choice to inform the indicator.

The next indicator, expenditures per capita, can receive information from three (3) inventory sources: the Canadian Institute for Health Information (with a total score of 57/70 or 81%), the Newfoundland Center for Health Information (with a total score of 59/70 or 84%) or the Non-Insured Health Benefits (NIHB) Patient Statistics (with a total score of 62/70 or 89%). The local source will contain a great deal of information about Labrador Inuit and will be used as a source for these clientele. Information on other individuals living within the region would have to be mined from the provincial resource – NLCHI - which does not break Labrador data out by aboriginal group and should therefore supply the needed information by comparison. This indicator would therefore require two (2) data sources.

The next seven (7) indicators; doctors and nurses per capita, hospital days per capita, CABG rates, hip replacement, knee replacement, hysterectomy rates and myringotomy rates; can be informed by two (2) sources: the Canadian Institute for Health Information (with a total score of 57/70 or 81%) or the Newfoundland Center for Health Information (with a total score of 59/70 or 84%). The provincial source has the better rating score and is also linked to the national CIHI information system; it therefore seems logical to have the NLCHI inform these seven (7) indicators.

6.6.14 **Matching CIHI Indicators to Inventory Data Sources**

Table 6.6.14a outlines the matching of eighty-five (85) Canadian Institute of Health Information (CIHI) indicators to the data sources relevant to the population of concern. (Please refer to **Appendix D** for a complete review of data quality and practicality rating scores, with total data rating scores for data sources remaining after the first stage elimination process.)

Table 6.6.14a **Matching of CIHI Indicators to Inventory Data Sources**

CIHI Indicator	**Data Source**	**CIHI Indicator**	**Data Source**
Deaths		Social Support	Labrador Inuit Regional Health Survey (LIRHS)
Infant Mortality	Public Health Death Books	Life Stress	
Perinatal Deaths		**Environmental Factors** – in developmental stages	
Life Expectancy		**Health System Performance (Acceptability)** – in developmental stages	
Circulatory Deaths		**Health System Performance (Accessibility)**	
Cancer Deaths		Influenza Immunization, 65+	Regional Immunization Database, Health Labrador Corporation
Respiratory Deaths		Screening Mammography, Women Age 50-69	Non-Insured Health Benefits (NIHB) Patient Statistics and Newfoundland Center for Health Information (NLHCI)
Suicide		Pap Smears, Women Age 18-69	Community Clinic and Hospital Registries, Health Labrador Corporation
Unintentional Injury Deaths		Childhood Immunizations	Regional Immunization Database, Health Labrador Corporation
Pertussis Deaths		**Health System Performance (Appropriateness)**	
AIDS Deaths		Vaginal Birth After Cesarean Section	Newfoundland Center for Health Information (NLHCI)
Potential Years of Life Lost		Breast Conserving Surgery	
Inequalities in Life Expectancy		Cesarean Sections	
Health Conditions		**Health System Performance (Competence)** - in developmental stages	
Overweight	Community Profiles	**Health System Performance (Continuity)** - in developmental stages	
Arthritis		**Health System Performance (Effectiveness)**	
Diabetes		Quitting Smoking	Labrador Inuit Regional Health Survey (LIRHS)

Asthma		Low Birth-Weight	Public Health Birth Books
Chronic Pain		Pertussis	Provincial Communicable Disease Control Database
Depression		Measles	
Injury Hospitalizations	Provincial Work Injuries Database	Tuberculosis	Regional Tuberculosis Database
Food and Waterborne Diseases	Provincial Communicable Disease Control Database	HIV	Provincial Communicable Disease Control Database
Activity Limitation		Chlamydia	
Functional Health	Labrador Inuit Regional Health Survey (LIRHS)	Pneumonia and Influenza Hospitalizations	Newfoundland Center for Health Information (NLHCI)
Disability Days		Deaths Due to Medically-Treated Diseases	Statistics Canada
Activity Limitation		Ambulatory Care Sensitive Conditions	Newfoundland Center for Health Information (NLHCI)
Health Expectancy		**Health System Performance (Efficiency)**	
Well-Being		Surgical Day Case Rates	Newfoundland Center for Health Information (NLHCI)
Self-Rated Health	In developmental stages	May Not Require Hospitalization	
Self-Rated Health "Excellent" Health for 2 Consecutive Years	Labrador Inuit Regional Health Survey (LIRHS)	% Alternate Level of Care Days	
Self-Esteem		Expected Compared to Actual Stay	
Mastery		**Health System Performance (Safety)**	
Health Behaviors		Hip Fractures	Newfoundland Center for Health Information (NLHCI)
Smoking Rate	Labrador Inuit Regional Health Survey (LIRHS)	**Community and Health System Characteristics**	
Youth Smoking Rate		Population Count	Administrative Enumeration System, Labrador Municipal Councils
Smoking Initiation		Teen Pregnancy/ Teen Births	Public Health Birth Books
Regular Heavy Drinking		Expenditures per Capita	NLCHI and NIHB
Physical Activity		Doctors and Nurses per Capita	Newfoundland Center for Health Information (NLHCI)
Breastfeeding	Community Profiles	Hospital Days per Capita	
Living and Working Conditions		CABG Rates	
High School Graduation	Provincial High School Transcript Information System	Hip Replacement	
Post-Secondary Graduation	Labrador Inuit Association Training and Education Database	Knee Replacement	

Unemployment Rate	Labrador Inuit Regional Health Survey (LIRHS)	Hysterectomy	
Long-term Unemployment		Myringotomy	
Youth Unemployment			
Low-Income Rate	Statistics Canada		
Children in Low Income Families			
Income Inequality			
Housing Affordability			
Crime Rate	Police Information Retrieval Information System (PIRS)		
Youth Crime Rate			
Decision-Latitude at Work	Statistics Canada		
Personal Resources			
School Readiness	Labrador School Board, Student Information System		

With the matching complete, **Table 6.6.14b** outlines the types of data sources available by name and number, the number of data sources actually used and the number of CIHI indicators to be informed by these sources.

Table 6.6.14b **Total Available Data Sources, Number of Data Sources Actually Used and Number of Indicators Informed By These Sources**

Type of Data Source	Total number of Data Sources Remaining After Elimination Process	Total number of Data Sources Actually Used	Number of Indicators Informed
Labrador Inuit	9 (30%)	6/9 (67%)	40 (47%)
Provincial	13 (43%)	7/13 (54%)	28 (33%)
Federally based (National)	2 (7%)	1/2 (50%)	6 (7%)
Community Level	3 (10%)	1/3 (33%)	1 (1%)
Municipal Council	1 (3%)	1/1 (100%)	1 (1%)
Policing	2 (7%)	1/2 (50%)	2 (2.5%)
Labrador Inuit and Provincial			2 (2.5%)
Developmental Stages	0	0	5 (6%)
Totals	30 (100%)	17/30 (57%)	85 (100%)

Of the eighty-five (85) indicators within the CIHI model, forty (40) or 47% can be informed by six (6) of the nine (9) Labrador Inuit sources. Twenty-eight (28) or 33% can

be informed by seven (7) of the thirteen (13) provincial sources. Six (6) indicators or 7% can be informed by one (1) of the two (2) national sources. One (1) indicator or 1% can be informed by one (1) of the three (3) community level sources. One (1) indicator or 1% can be informed by the one (1) Municipal Council data source. Two (2) indicators or 2% can receive information from both a Labrador Inuit and a provincial data source.

CHAPTER SEVEN: Discussion of Results

7.0 Introduction

This project has investigated the scope and content of various health and social data sources relevant to Labrador Inuit and has provided a good working knowledge of which components might be applicable to the task of selecting a model to measure health status. This chapter will discuss the results of the inventory and make a number of suggestions as to how a health status monitoring system might actually be made functional.

7.1 Study Purpose

A health care organization needs health information to inform programs and services. While there are many sources of data within the health care realm, health delivery agencies are not always aware these sources exist, of their location, of their usability or applicability. This study was undertaken to review health status monitoring models, to uncover relevant data sources and to critically appraise and rate available information.

These data sources, then framed within the context of the Canadian Institute of Health Information (CIHI) health indicator model, can be used by our aboriginal health care organization to measure health status and thus guide decision making around service delivery. This study provides the fundamentals necessary to measure the health status of the population of concern.

7.2 Model Strengths and Limitations

The project uncovered a wide variety of population health monitoring models. All of these models had varying strengths and limitations. The Canadian Institute of Health Information (CIHI) has developed a model which seems to be able to reflect the needs of

our particular client base. For our region of the world, this model best met the following criteria:

a) It was built by consensus;
b) It is a close match to the required organizational indicators;
c) The indicators within this model are available in the region through currently available data sources;
d) The model is readily adaptable to meet organizational needs;
e) Resources are available to adapt this model for use in the region in a timely fashion.

The CIHI model, while also being used by Inuit Tarpirisat of Canada (ITC) in their review of health service delivery models, is relatively new (May 1999) and unrefined; an evaluation of the model would have been preferred prior to accepting its indicator set. As well, the CIHI Consensus Conference noted that information sources are not yet available or not adequately developed for the following indicators: environmental health factors, acceptability of health system performance, competence of health system performance, and continuity of health system performance (CIHI, 1999). With our health care organization currently exploring the development of environmental health programs and services, the lack of operationalized indicators in this area is a significant limitation. (It is important to note these indicators are in the developmental stages and will be included in the very near future.)

Further, a number of confirmed CIHI indicators are under review for feasibility, comparability and availability of data (CIHI, 1999).

7.3 How the Data Sources Were Rated

Simmes et al suggested that the impact of changes in policy and in services and programs can be monitored through the use of data collected from other sources (Simmes et al, 2000). Much of the data reviewed for this project were collected by organizations for other, largely administrative purposes. Some method for reviewing these information sets in a consistent and clearly understandable format had to be developed. A review of the literature uncovered a number of examples of data source reviews.

Goldman et al, in looking at environmental health surveillance, suggested that data collected for other purposes may not be sufficient for such purposes (Goldman et al, 1992). Holzner suggested that other limitations of such data sources may include lack of timeliness of data collection or data availability, incomplete data on outcomes, and problems with data quality (Holzner et al, 1993). Thacker suggested that data should be retained in archival form, not only to document the evolving health status of a population, but also to provide an understanding of the predictors of disease and injury (Thacker et al, 1996). Thacker further went on to say that these data should be of the best possible quality. He and his colleagues suggested a framework for categorizing systems for environmental community health surveillance. Thacker's framework suggested using categories such as timeliness, completeness, representative-ness, data quality, and utility at various levels of government (Thacker et al, 1996).

The Health Data Technical Working Group (Health Canada, 1999) suggested that potential data sources be rated as to data quality (accuracy and comparability). This group also stressed the need for data sources that were readily available, comparative among regions and broadly related on health outcomes and demographic variables.

The Centers for Disease Control and Prevention (CDC) suggested that the evaluation of community health surveillance systems can involve an assessment of system attributes

including simplicity, flexibility, acceptability, sensitivity, positive predictive value, representative-ness, level of usefulness and timeliness (CDC, 2000).

Thus, a number of consistent evaluating factors emerged with which to review data sources. The factors tended to sort into two categories, that of data quality and data practicality. These categories were drawn upon to evaluate data sources for this project. The available data sources were rated for data quality and data practicality using a Likert scale with seven (7) categories each and five (5) rating steps. This rating system was largely developed by the researcher using criteria suggested in the above noted literature.

While the literature regarding data information source rating is not well developed, the use of a Likert scale to quantify elements of the data source inventory seemed to be an appropriate fit (Likert, 1952). Ordinal level variables, such as those used within the project could be named, ranked and hence quantified. Rules for ordinal level measures indicate that these data can then be counted and placed in rank order (Summer, 1993). It was then expected that those with the highest rating would be utilized to inform the health status monitoring tool.

7.4 **Strengths and Limitations of Data Sources**

Thacker suggested that a surveillance system is only as good as the data informing the system (Thacker et al, 1996). Thus the usage of data sources that are of questionable quality will yield a health monitoring system that is also of questionable quality. The reverse also applies. The review of the various data sources revealed a number of strengths and limitations, which will be outlined and discussed in the following section.

7.4.1 **Sensitivity, Validity and Specificity**

While it would have been advantageous to have scored the data using the criteria of sensitivity, validity and specificity, this classification proved to be well nigh impossible. For example, the measurement of a system's sensitivity requires the collection of, or access to, data external to the system to determine the frequency of the condition in the community and validation of the data collected by the system (CDC, 2000). Examples of external (independent) data sources for assessing the sensitivity of health information or surveillance systems include individual medical records, registries, and estimations of total cases in the community. This type of review was well beyond the scope and access capability of this project.

7.4.2 **Data Gaps**

It is well recognized that information gaps have hindered Inuit and government efforts to engage in effective policy analysis and policy and program development (Inuit Tapirisat of Canada [ITC], 2000). The data sources uncovered are the foundation for the building of a regional Inuit health status monitoring system and the development of effective program policies. While there are a number of gaps in the information that would be currently available to begin the system, these are not gaps that would hamper the system, but are rather local information needs that would be helpful in measuring health and subsequent outcomes of programs and services.

Thacker, in his framework for surveillance for environmental health, suggested that community health officials need to identify useful existing data systems, as well as gaps in these systems that need to be filled by new resources (Thacker et al, 1996). The project has identified the existing systems. Components of Thacker's framework and others (CDC, 2000; Health Canada, 1999; Goldman et al, 1992; Holzner et al, 1993) were used

to develop a conceptual basis, through which informational strengths, gaps and limitations have been revealed.

Hancock sees it as imperative that indicators for a small population use data that are as close to the community level as possible. This usage gives a clear and accurate picture of what is going on in the community and the region. The accurate picture provides for a better allocation of programs and services and actually makes sense to the community (Hancock et al, 1999). While all eighty (80) of the active CIHI indicators will be informed by seventeen (17) or 57% of the thirty (30) remaining information sources, not all the data sources are those of choice. For each CIHI indicator, the project is unable to provide local or at least provincial based data as the sources do not currently exist. Six (6) or 7% of these indicators must be informed from national level sources.

Community and regional level data are generally readily accessible and provide the detail needed for local health policy decision-makers. Community and regional programming need readily accessible data. This project inventory outlined nine (9) usable Labrador Inuit data sources, six (6) of which can inform forty (40) or 47% of CIHI health indicators. A further twenty-eight (28) indicators or 33% can be informed by provincial sources – a source that is more accessible than a national source. The remaining six (6) (7%) developed indicators can be informed by: community data (1%), municipal council data (1%), policing data (2.5%), and a combination of Labrador Inuit and provincial data sources (2.5%). Five (5) indicators (6%) are still in the developmental stages.

The indicator set chosen was not built for an aboriginal group and thus does not contain culturally appropriate/ specific indicators. This indicator set does not provide an opportunity for the aboriginal health care organization to track and monitor a number of indicators which are seen to be important by the aboriginal health care group, such as: the process of language retention (number of Inuit speaking the aboriginal language, number of children being taught Inuktitut in school, number of children being taught Inuktitut in

Child Care programs); wild-food consumption and food security; hunting, fishing and gathering activities and so on. It will be suggested that culturally appropriate indicators be developed to supplement the indicator set.

7.4.3 **Data Utility**

The study was proposed to inventory accessible and usable data. When considering utility, published data from national sources such as Statistics Canada or the Canadian Institute Health of Health Information (CIHI), is often presented in summary graph form. These graphs usually lack precise figures or data are presented in the form of reported cases without a population base or denominator provided with which to calculate a rate for the region of interest. Similarly, census data are often randomly rounded up or down to a multiple of five (5) or offered as a percentage rate of the whole population rather than as a rate per 1,000 or 100,000 population. The rounding up or down of data is significant when communities are small. Thus the national information used to inform six (6) indicators would have to be interpreted with care.

This data assessment has indicated that small population issues (e.g. small samples within a national population – as experienced with the national holdings), clumping of data (i.e. lumping information for the various aboriginal groups of Labrador in with the general population [which has occurred with the NLCHI information source], therefore resulting in inappropriate data for regional service delivery analysis), and a lack of timely and complete information are important limitations among the data holdings. The reviewer was assured that provincial agencies were aware that the clumping of aboriginal data with that of other residents of the region was a problem, and were investigating ways to improve the situation.

The use of a health status measuring model with fewer indicators (such as Healthy People 2000 - Model E) might have overcome the problem of data gaps (i.e. fewer indicators

require less information), but would not have provided the broad base of indicators that are needed by our health care organization to evaluate programs, services and community health status, as outlined in **Appendix A**.

7.4.4 **Duplication of Data**

The Working Group on National Food and Nutrition Surveillance System (2000) suggested that an effective surveillance system for their purposes needs a range of data sources to provide timely, reliable, ongoing information. Maybe there is not *one best source* and community level indicators should be informed by a number of complimentary sources. The results of this inventory had this actually occurring in two (2) instances – where a Labrador Inuit data source (the Non-Insured Health Benefits Program Patient Statistics [with a total data rating score of 62/70 or 89%], will be used to inform on *Screening Mammography* and *Expenditures per Capita* for Labrador Inuit and the Newfoundland Center for Health Information (NLCHI), [with a total data score of 59/70 or 84%], regional report for Labrador, will provide the information on the non-Inuit population.

Several health indicators can be monitored through a number of data holdings held at the various levels. For example, *Mortality Information* can be obtained from four (4) sources, ranging from a local to a national level. The consequence of such duplication could be uncertainty on the part of users with respect to which source to use, potentially conflicting information and an inefficient use of scare resources. This project provides evidence that credible community level data can be used where at all possible as the information has consistently received a higher rating score (i.e. Public Health Birth Books had a total score of 66/70 [94%] as compared to 54/70 [77%] for the provincial source and 52/70 [74%] for the national source). Community level data is the necessary information when looking at outcomes from programs and services delivered by community agencies; use of this data makes sense.

7.4.5 **Information Sharing and Dissemination**

The Health in the Mersey Project (Model B) pointed out that much routinely collected data of relevance to health promotion was not being utilized because it was collected by non-health agencies. We hope to rectify this shortcoming in the local region with the data source inventory.

The Working Group on National Food and Nutrition Surveillance System (2000) stressed that surveillance information must be effectively communicated to those who need to know. Surveillance results must be analyzed, summarized, interpreted and disseminated in ways that are accessible and useful to decision makers. Hancock felt that this suggestion should go a little further, with the provision of accessible and understandable information for community members (Hancock et al, 1999).

The Labrador Inuit Regional Health Survey (LIRHS) [which received a total rating score of 53/70 or 76%] is an example of timely and appropriate information dissemination to clients and stakeholders. Data were fed back to respondents, communities and agencies via a series of nine (9) newsletters – newsletters that provided the results of the survey in the context of everyday life, while also promoting health enhancing lifestyles and behaviors. This example is cited to indicate that the health care organization of concern is aware of how to give information back to its clientele, but has yet to implement a comprehensive data collection system.

The Working Group on National Food and Nutrition Surveillance System (2000) stated that surveillance databases must be publicly available and accessible to those who need to work with the detailed data. Access must be timely and affordable. Contrary to this suggestion, one (1) national data source, Statistics Canada, is neither timely nor affordable. But we are obligated to make use of it to inform six (6) of the CIHI indicators

because of its broad range and many variables, and because local information for these indicators is not presently available

Thacker suggested that community health officials need information in order to set priorities in a responsible manner, and regular dissemination of data is a critical mechanism for providing information. He further states that the dissemination of data is the element of surveillance that has received the least attention (Thacker et al, 1989). It is anticipated that this inventory will help to address this omission.

The Centers for Disease Control and Prevention (CDC) suggest a number of options for disseminating data and/ or information from the system including electronic data interchange, public-use data files, the Internet, press releases, newsletters, bulletins, annual and other types of reports, publications in scientific journals, and poster and oral presentations (CDC, 2000). A number of the systems reviewed are able to disseminate information on a regular basis: the provincial Communicable Disease Control system (quarterly newsletters), the Work Injuries Database (quarterly health and safety newsletters), the Labrador Inuit Regional Health Survey (a series of nine one-time newsletters outlining survey results in everyday language), the Non-Insured Health Benefits system (quarterly reports to stakeholders on client service usage), Statistics Canada (reports are produced from the Census, which have to be purchased), as well Statistics Canada has posted some of its information on its website for public review and use.

7.4.6. **Use of Existing Resources**

Data sources, in the project rating criteria, were said to have an adequate support network if there was a system in place to support the database i.e. resources, input staff, etc.

Choi suggests that a comprehensive surveillance system should be based mainly on existing routine data collection, rather than creating an entirely new system. In other words, planning, updating, prioritization and better coordination could put existing resources to better use (Choi, 1998).

Data analysis is often difficult because original source information is not always available. A possible solution would be the expansion of the existing descriptive data holdings to a data warehouse of the core program area data holdings (Health Information Management Working Group, 1998). The process of centralizing data should result in a reduced number of information systems and storage sites, as well as a simplified information structure. It would also be useful to expand the data warehouse to all core program areas and link to data after obtaining technical input on frequency of update, data standards, technical specifications and software standards. Central information storage will impact positively on information sharing capacity.

This suggestion would be beneficial to the eleven (11) total Labrador Inuit databases, which have been developed by the health care group and its affiliates. There is currently a great deal of information in-house, information that is linked by the Labrador Inuit Association (LIA) membership number, information that could be better coordinated and warehoused. The proposed health indicator set could be the foundation for a coordinated, integrated system.

7.4.7 **Data Accessibility**

An accessible data source, in the project rating criteria, was said to house readily-shareable, user-friendly data.

Thacker suggested that timeliness of access to data is also an issue within the science of health surveillance (Thacker et al, 1994). Provisional information from many important

data sources, such as vital records and reports of notifiable diseases, should be available immediately. In this respect, Thacker argued, other data sources may enable more timely detection of changes in health practice.

When data are analyzed and interpreted, they become *information*, which is of value to policy makers, program managers and other decision makers. Hancock states that when the information is translated into a form that is useful to the community – and even more important, when the definition of the information to be collected, as well as the analysis and interpretation, is in the hands of/ accessible to the community – then that information becomes useful *knowledge*, and the process of acquiring and using that knowledge helps to empower the community (Hancock et al, 1999). It is hoped that the distillation of the data from the health status monitoring tool will result in wise choices and informed decision making for local health care providers.

All the data sets reviewed were owned and operated by various governmental and non-governmental organizations. Much of this information is perceived to be inaccessible or somewhat inaccessible. Government departments, where financial restraint is the order of the day, do not often have time to return calls or respond to messages. While this challenge has been somewhat alleviated by the development of the Newfoundland Center for Health Information (NLCHI) [with a total data score of 59/70 or 84%], whose job it is to respond to information needs, many of these departments still maintain databases necessary to inform the proposed system. It is interesting to note that five (5) [17%] of the twenty-nine (29) possible provincial systems reviewed were removed in the first phase of the elimination process because the sensitive information in these systems is not available for public use, but rather is used to inform care providers only.

Increased access to data among all stakeholders is a simple way to increase research efficiency (Health Information Management Working Group, 1998). Further, even though there is a great deal of information available about the client population, our

various information officers have limited access to information. This is likely due to not being made aware that some of the information exists and/ or how to access needed statistical data. It is expected that this project will at the very least heighten awareness of available information sources.

7.4.8 **Data Archives**

Data sources archives, within the project, were rated as to whether this data is retained in readily accessible archival form.

To overcome the issue of questionable data, the Health Data Technical Working Group (Health Canada, 2000) recommended that three years of data be supplied to their project in order to properly access data quality. While all thirty-four (34) data sources were rated for data practicality, with one criteria being an accessible archival form, only three (3/34 or 9%) received a rating score of three (3) or less (i.e. a rating of 3 = sometimes archived). It can therefore be argued that thirty-one (31/34 or 91%) data sources have at least three years of available information.

7.4.9 **Effectiveness of Information Gathering Activities**

Thacker argues that whatever data collection method is used, it should be systematic and appropriate for the community health program that it serves. In addition, data quality control and quality assessment are important to any data gathering activity (Thacker, Berkelman and Stroup, 1989). This study has looked at data quality and practicality from a external research perspective, which is not the same type of investigation that would be conducted by data source owners when reviewing their in-house systems.
POPULIS (Model A) is an excellent example of ongoing, consistent data gathering activities – albeit from an administrative point of view – but effective and useful none-

the-less. This model draws on linked health service utilization data, an advantage that our region unfortunately does not have.

Stakeholders must ensure that information gathering activities are efficient, effective and ongoing (CDC, 2000). The hard copy information systems maintained by the Moravian Church in Labrador are examples of efficient, consistent and effective data gathering systems. This system scored consistently well in the data quality and practicality rating system, with a total data score of 66/70 or 94%. Staff and volunteers within the church have been and are committed to maintaining the system and entering data as it becomes available.

Good examples of well-maintained data collection systems are the provincial Communicable Disease Control (CDC) database (with a total data score of 68/70 or 97%) and the policing data source (with a total data score of 64/70 or 91%). These systems scored consistently well on data quality and practicality ratings. Sponsoring organizations require that personnel update the systems weekly and consistently interface with the system; this requirement facilitates effective data gathering, familiarization with the system, accessibility, and ease of usage.

Of the nine (9) Labrador Inuit data sources remaining after the first stage elimination process, three (3) sources [the NIHB Patient Statistics (with a total data score of 62/70 or 89%) and the Birth and Death Books (with individual total data rating scores of 66/70 or 94%)] have very effective data gathering activities; that is the systems are consistently maintained and updated. Within the annual work plan process undertaken within our organization (a process necessary to monitor service delivery and the outcome of programs), it is necessary to establish a review of information collection activities and an identification of changing information and resource requirements. Central information storage and information sharing will also reduce redundant data gathering and entry and help bring rating scores up for those data systems that were having difficulties.

A suitable and effective system must provide the capacity to monitor trends and anticipate and respond to emerging information needs, including those of special populations (Working Group on National Food and Nutrition Surveillance System, 2000). While the researcher was unable to investigate the analysis methods of all information sources at great depth, it appears that not all data holdings conduct an adequate detailed analysis required to produce meaningful and useful information for decision making. It seems necessary to increase the time that research staff spend analyzing and interpreting data and to improve coordination of data analysis and interpretation. The allocation of sufficient human and financial resources to research programs and projects would be beneficial.

The provincial Communicable Disease Control (CDC) [with a total data score of 68/70 or 97%] database is an example of a regularly analyzed and monitored system. Quarterly reports are formulated from information received on a weekly basis from CDC staff. This information is forwarded to community health staff and can then be used to monitor trends over time for their regions. (Unfortunately the report for Labrador contains information for the entire region. We are therefore unable to pull out information about Labrador Inuit communities from this particular report. However, the regional CDC database is able to overcome this limitation and provides our organization with community specific reports.)

This project supports the need for organizations to put financial and human resources into data collection so that the next steps of analysis and interpretation can be emphasized. The author feels that more research is necessary in this area of the data inventory review.

7.5 **Data Source Coordination**

The project was undertaken as an administrative review and community consultation will occur after the results have been documented. This is contrary to the process envisioned

by Hancock et al in their conceptual framework (Model F) for measuring population health at the community level (Hancock et al, 1999) – i.e. consultation and then review.

In order that the many and varied data sources uncovered in this inventory be better coordinated and utilized, it is suggested that a local Data Advisory Committee be developed. The group could be made up of in-house staff and representatives of other stakeholder agencies. Chamberlayne suggests that the role of a Data Advisory Committee (DAC) would be to:

- review health issues and advise on priorities for research and surveillance;
- advise on and assist with the refinement of core indicators for regional level information;
- consult on the form in which data are released to researchers;
- give advice as to the conditions under which analyses would be undertaken;
- advise on data security arrangements;
- review incoming data for expert interpretation;
- formulate communication outputs;
- further refine research and surveillance efforts;
- facilitate implementation of health indicator set usage;
- give advice on research requests;
- develop and advise on reporting mechanisms and policies; and
- assist with the development of data sharing protocols between various stakeholder agencies (Chamberlayne et al, 1998).

The author recommends that the proposed health status monitoring system be refined over time. Hancock suggests that this process include local involvement/ collaboration in indicator selection (Hancock, 1999) rather than choosing a model which already contains an indicator set. This study has acted contrary to Hancock's recommendations in the

interest of expediting the process and building a foundation from which to act. The organization of concern is delivering many programs and services but does not have a tool to evaluate effectiveness of these programs and services.

7.6 **Overall Project Limitations**

The project, while an extremely valuable undertaking to the researcher and to the health care agency of concern, was not without a number of overall limitations:

a) the review provides one snapshot in time of the databases available and may not be accurate within six (6) months;
b) bias could have been introduced into the data source review. The researcher attempted to be objective when reviewing and rating the databases. From the literature, established objective criteria were used, as were standard definitions, and protocols. These standards were consistently applied to the data source inventories;
c) the information sources concern a small population and as such may impede generalizability of the results beyond the population of concern;
d) twenty-two (22) or 73% of the possible thirty (30) respondents actually provided interviews to the project, the remainder of the information was obtained through research. A personal interview with the eight (8) non-respondents might have yielded more useful / additional information;
e) while all relevant databases were rated and scored, some sources had to be utilized irrespective of the score as they were the only ones currently available;
f) the researcher did not conduct a site visit to all data sources. Therefore a detailed review of data analysis methods was not undertaken. Further research is needed into this portion of the data source inventory;
g) while no effort was made to define or redefine the health status measures that would be specific to this project, the compilation of the data presented some challenges and difficult choices. Many northern communities such as ours have

small populations and to calculate the rate of an indicator in terms of cases per 1,000 or 100,000 is to extrapolate low numbers into terms and proportions that exceed the population of the community or region. These calculated rates will have to be produced and interpreted with caution.

On the whole, general trends and similarities across the country can be identified from this study (i.e. Vital Statistics, administrative databases, etc.) and may be useful for other organizations involved in aboriginal health care at various levels.

CHAPTER EIGHT: Conclusions and Recommendations

8.0 Introduction

Health information, and the measuring of health status, center around collecting, analyzing, and sharing information about a range of population health indicators. During the course of this project, data holdings and health status indicators were identified and reviewed in order to judge strengths and weaknesses of data sets relevant to the clientele of concern, and to further make recommendations to improve data collection and surveillance.

Data holdings were identified and assessed through an elimination process, followed by the utilization of a rating system to determine the most appropriate sources of data for the proposed health monitoring system. The Canadian Institute of Health Information (CIHI) Indicator Model was selected as the model of choice. The result is a concise list of core indicators and corresponding sources that can be used to monitor Labrador Inuit Population Health. This list can be used as a broad surveillance tool that acts as a "red flag" to signal changes in population health and to demonstrate a need for action (CDC, 2000). The comprehensive list of eighty-five (85) indicators identified is also available as a resource.

Core population health indicators for Labrador Inuit and corresponding data holdings must encompass all relevant areas of the population health model and must employ the best alternatives for information sources, definitions and operationalizations of health indicators. Achieving this goal will ensure that our organization employs the most efficient and effective broad based surveillance tool available while minimizing uncertainty and ambiguity.

Core health indicators must reflect stakeholder priorities and must be feasible in terms of accurate data collection. The indicator list should be a concise system to alert decision makers on key issues when required. To this end, health indicators must be reviewed regularly to ensure that the best available indicators are being used and that they are in tune with community needs.

8.1 Conclusions

During the analysis of the compiled inventory, it became evident early on that many agencies collected health status information in varying formats and for varying reasons. Further, the majority of these agencies did not necessarily communicate or share their findings with each other or with the people being investigated. While many of these health information systems were not as well maintained as they could have been, their very existence was confirmation of a realization of the need for information to drive programs and services.

How can the health status of a small population be most effectively measured, utilizing currently existing data systems? Can the data systems be modified or adapted to fit regional needs? Are there additional measures that do not exist or are incomplete? How can the collection of these additional data be ensured? Can a health status monitoring tool be proposed for the population of interest as the basis for a monitoring system? Will this mean the development of a new tool or the adaptation of a currently utilized population health tool? The evidence in total indicates that a great deal of information exists about the population of concern. This current information can be used to measure health status. As well, a number of excellent tools have been developed to measure population health; one of these tools can be adopted to fit our organizational needs at this time. The Canadian Institute for Health Information (CIHI) model is most suitable for the health status monitoring needs of the population of concern. A number of culturally specific indicators need to be developed to meet organizational needs. As well, several indicators

within the model are in the developmental stages and should be followed through for incorporation into the monitoring process.

8.2 **Recommendations**

The following recommendations evolved out of this data review, while visualizing the needs of the health indicator set and the aboriginal health care systems both present and future.

A. When implementing the health status indicator set, it is strongly suggested that the health care organization use community level data where feasible.

> This project strongly suggests that the credible community level data be used where at all possible as this information has proven to be timely, cost efficient, accessible, etc. Community level data is the necessary information when looking at outcomes from programs and services delivered by community agencies – use of this data makes sense.

B. Health care organizations are encouraged to provide ongoing funding and personnel to health information management and research to ensure maintenance, updating and appropriate analysis.

> There is a need for sufficient human and financial resource allocation to research projects, programs and databases with cooperation and commitment from all stakeholders. Management is advised to review personnel and financial resources to allow optimal action, with working groups set up to develop components, content, collection and analysis with the assistance of external expertise where required.

C. Health care organizations are advised to evaluate and review health indicators regularly so that they are current, responsive and useful.

As a first step in the review and evaluation of the indicator set, it is suggested that culturally appropriate indicators be developed immediately.

D. Environmental health indicators should be developed as soon as possible.

With our health care organization currently exploring the development of environmental health programs and services, the lack of operationalized indicators in this area is a serious omission. The development of environmental indicators is recommended. A follow-through with the forthcoming development of CIHI environmental indicators is recommended.

E. Standardized data collection guidelines are required among all stakeholders.

Standardized indicators for levels of data aggregation are required to facilitate data collection and analysis. It is also important to establish a consensus on data quality, definitions, collections, and sharing guidelines. A further critical evaluation of the quality of data should be made with suggestions provided for improvement. Standardized software for automation of data collection, storage and analysis will also greatly improve the process.

F. Consistent and ongoing data collection is strongly recommended.

Data collection organizations are encouraged to put funding and human resources into data collection so that the next steps of analysis and interpretation can be emphasized.

G. Enhanced coordination and integration of Labrador Inuit databases is strongly suggested.

The Labrador Inuit databases are an excellent source of program information, but time and attention need to be paid to maintaining these systems. It will also be important to match newly developed indicators to data sources so that the system can be informed, respond to and reflect changing community needs.

H. More research is needed into the critical evaluation of the quality of available data.

Because this research project was unable to investigate the analysis methods of all information sources at great depth, it is recommended that ongoing evaluation and updating of data sources occur.

I. A Data Advisory Committee (DAC) is needed immediately.

A Data Advisory Committee (DAC) or Coordination Group is required to provide advice on information needs, reporting mechanisms, and other data coordination and utilization issues.

8.3 Next Steps

Once the population health status indicator model has been accepted and implemented, it can be refined and enhanced by consulting a variety of people involved with the tool, and by checking the planned uses of the tool against direct observation. It will also be necessary to describe the components of the planned health information system, for example:

a) What is the population being monitored?

b) What is the period of time of the data collection?

c) What data are collected?

d) What are the data sources? Who provides the data?

e) How are the data transferred, stored and/ or backed up?

f) Does the system comply with applicable standards for data formats and coding schemes? If not, why?

g) Who edits the data? How and at what levels are the data edited? What are the checks for data quality?

h) Who analyzes the data? How are the data analyzed and how often? How does the system ensure that appropriate scientific methods are used to analyze the data?

i) What preliminary and final tabulations or reports are produced?

j) How often and in what form are the system's data disseminated? To whom and how frequently are these data disseminated?

k) What procedures are in place to assure confidentiality of the data, such as mechanisms to obtain consent for disclosure of identifiable health data when necessary or penalties for unauthorized disclosure of data? Does this process comply with applicable federal and provincial statutes and regulations?

l) What is the policy for releasing data?

m) What efforts are made to inform affected communities about the health status monitoring system?

n) Does the system comply with an applicable records management program? For example, are the system's records properly achieved and /or disposed of?

o) What would be the cost of the system? Can the organization estimate person-hours and actual overhead costs for maintenance, capital costs, and report production?

The population health model refinement for Labrador Inuit has attempted to respond to the first four questions. It is now important to define/ determine the next steps in the process. The indicators that need to be examined over-time have been identified, this project has uncovered the sources of the data (where possible) and has suggested a measurement tool. There is still a great deal of work to be undertaken.

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APPENDIX A

Organizational Indicators and Data Sets Required for Program and Service Evaluation

Program – Tobacco Use Prevention

Indicators (with targets in brackets)

- % of adult males and females that do not use tobacco (increase from 28% in 1991 to 50% in 2000)
- % of adolescent boys and girls aged 12 to 18 that do not use tobacco (increase from 43% in 1997 to 90% in 2000)
- % of population not exposed to second-hand smoke daily (increase from 50% in 1997 to 20% by 2000)
- % of schools with tobacco reduction in curriculum (100% by 2000)
- % of workplaces that are smoke free (100% by 2000)
- % of workplaces where provincial smoke-free legislation is enforced (100% by 2000)
- % of communities with smoking cessation programs (100% by 2000)
- % of communities with smoke-free public places legislation (40% by 2000)

Data Sets Required

- # of males and females age 19 years or older
- # of males and females age 12 to 18
- # not exposed to second hand smoke
- # of schools
- # of schools with tobacco reduction in curriculum
- # of smoke-free schools
- # of workplaces
- # of workplaces with no smoking
- # of communities
- # of communities with smoke-free public places legislation

Program – Nutrition Promotion

Indicators (with targets in brackets)

- % of population with sound nutrition practices
- # of population in healthy weight range
- # of population with access to sufficient nutritious, culturally appropriate and personally acceptable foods
- % of schools with nutrition education program (100% by 2000)
- % of schools with nutritious food policies (100% by 2000)

Data Sets Required

- population by age and gender
- # of adults, children and adolescents participating in daily physical activity
- # of schools
- # of schools providing daily physical activity

Program – Reproductive Health

Indicators

- % of pregnancies that are planned
- % of pregnant parents who participate in prenatal classes
- # of teen pregnancies per 1000 population of females under age 20
- % of live births that are low birth weight (< 2500 g)
- rate of premature delivery
- % of pregnant women who smoke during pregnancy
- % of pregnant women who use alcohol during pregnancy
- % of women who had a Pap Smear in the last three (3) years
- % of women over 50 who had a Mammogram in the last two (2) years
- % of sexually active adults who practice safer sex consistently

Data Sets Required

- # of women by age group
- # of deliveries annually
- # of live births
- # of live births < 2500 g
- # of pregnant women who smoke, use alcohol, attend prenatal classes
- # of Pap Smears and Mammograms performed in the last year
- # of planned pregnancies

Program – Sexually Transmitted Diseases

Indicators

- annual incidence of chlamydia
- annual incidence of primary, secondary and tertiary syphilis
- annual incidence of gonorrhea
- annual incidence of HIVand AIDS
- annual mortality rate for AIDS
- annual incidence of congenitally acquired STDs
- % of clients with notifiable STDs followed-up as per protocol
- # of clients for whom appropriate partner notification was conducted
- % of schools with sexual health included in the school curriculum

Data Sets Required

- # of cases of chlamydia, syphilis, gonorrhea, HIV and AIDS per year

- population by age and gender
- # of cases followed appropriately
- # of partners to be notified and # who were successfully notified
- # of schools with sexual health in curriculum
- # of schools

Program – Vaccine Preventable Diseases

Indicators

- annual incidence rates for pertussis, diptheria, tetanus, polio, influenza B, hepatitis B, measles, mumps, rubella
- annual # of reported laboratory confirmed influenza cases
- vaccine coverage rates as per national targets for MMR, diptheria, pertussis, polio, tetanus, hepatitis B, influenza, pneumococcal vaccine

Data Sets Required

- # of cases of pertussis, diptheria, tetanus, polio, influenza B, hepatitis B, measles, mumps, rubella
- # of vaccinations by age group and indication
- vaccine cohorts by age group

Program – Tuberculosis Control

Indicators

- annual incidence rate of active and reactivated TB
- % of TB contacts per case followed as per protocol
- acceptance rate for INAH prophylaxis
- compliance rate for TB chemotherapy
- % of cases on directly observed therapy (DOT)

Data Sets Required

- # of cases of TB
- # of contacts of each case
- # of contacts followed as per protocol
- # of individuals for whom INAH was recommended and # for whom it was accepted and for how long

Program – Outbreak Control

Indicators

- % of outbreaks managed as per protocol

Data Sets Required

- # of outbreaks investigated and managed per year
- # of individuals meeting the case definition for the outbreak per year

- completed report on each outbreak with recommendations

Program – Water Quality

Indicators

- % of communities with community water supply and distribution systems
- % of communities with water treatment programs i.e. chlorination
- % of communities with water sampling program as recommended in Canadian Drinking Water Guidelines
- % of communities whose water meets Canadian Drinking Water Guidelines on a consistent basis

Data Sets Required

- # of water samples done in each community
- # of samples that meet the guidelines
- description of water supply, treatment and distribution systems in each community

Program – Rabies Control

Indicators

- % of exposures to potentially rabid animals that are dealt with as per protocol

Data Sets Required

- # of human exposures to potentially rabid animals
- # of doses of rabies vaccine and rabies immune globulin used annually
- regular reports from appropriate provincial departments on prevalence of rabies in animal population
- # of rabies vaccinations given to animal population each year

Program – Emergency Response

Indicators

- % of communities with up to date Emergency Response plans
- % of communities who have practiced their plans within the last year
- % of staff of the organization who have attended local workshops on Emergency Response
- % of staff who have attended Emergency Response training at the national training center

Data Sets Required

- written copies of Emergency Response plans from communities
- debriefing reports from communities who have practiced their plans
- # of local workshops
- record of attendees at local and national workshops

Program – Non-Communicable Disease Prevention

Indicators

- incidence of cancer in the population of concern (morbidity and mortality)
- incidence of cardiovascular disease
- mortality rates overall
- hospital admission and discharge rates
- rates of clinic visits and for what cause
- % of women who have had Pap Smears or Mammograms as per guidelines
- risk factors for cardiovascular disease
- see also under Tobacco Reduction, Reproductive and Nutrition Promotion Programs

Data Sets Required

- population by age and gender
- deaths from all causes, especially cancer and cardiovascular disease
- Nursing Station data

Program – Dental Health

Indicators

- decrease in dmf (decayed, missing, filled) scores
- % of school children screened
- % of communities with adequate fluoride programs
- % of schools with dental health in curriculum

Data Sets Required

- dmf scores
- # of schools
- # of schools with dental health in curriculum
- # of fluoride mouth rinse programs

Program – Mental Health

Indicators

- mortality rate from suicide
- incidence of suicide attempts
- mental health plan
- incidence of depression
- % of communities with Crisis Intervention Teams
- % of communities with access to Crisis Hotlines
- % of staff trained in mental health issues and Crisis Intervention

Data Sets Required

- # of deaths from suicide

- # of suicide attempts
- # of calls to Crisis Hotline
- # of incidents requiring Crisis Intervention Team
- # of clients with depression

APPENDIX B

Health Indicators – Confirmed at the Consensus Conference (May 1999) – Canadian Institute for Health Information

Health Status			
Deaths	**Health Conditions**	**Human Function**	**Well-Being**
Infant Mortality	Overweight	Functional health	Self-rated health - In developmental stages
Perinatal deaths	Arthritis	Disability days	Self-rated excellent health for two consecutive years
Life expectancy	Diabetes	Activity limitation	Self-esteem
Circulatory deaths	Asthma	Health expectancy	Mastery
Cancer deaths	Chronic pain		
Respiratory deaths	Depression		
Suicide	Injury hospitalizations		
Unintentional injury deaths	Food and waterborne diseases		
Pertussis deaths			
AIDS deaths			
Potential years of Life Lost (< 75)			
Inequalities of life expectancy			
Non-Medical Determinants of Health			
Health Behaviors	**Living and Working Conditions**	**Personal Resources**	**Environmental Factors**
Smoking rate	High school and post secondary graduation	School readiness	In developmental stages
Youth smoking rate	Unemployment rate	Social support	
Smoking initiation (average age)	Long term and youth unemployment	Life stress	
Regular heavy drinking	Low income rate		
Physical activity	Children in low income families		
Breastfeeding	Income inequality		
	Housing affordability		
	Crime rate and youth crime rate		
	Decision-latitude at work		
Health System Performance			
Acceptability	**Accessibility**	**Appropriateness**	**Competence**
In developmental	Influenza	Vaginal birth after	In developmental

stages	immunization, 65 plus	caesarean	stages
	Screening mammography, women age 50-69	Breast-conserving surgery	
	Pap smears, age 18-69	Caesarean sections	
	Childhood immunizations		
Continuity	**Effectiveness**	**Efficiency**	**Safety**
In developmental stages	Quitting smoking	Surgical day case rates	Hip Fractures
	Low birth weight	May not require hospitalization	
	Pertussis	% alternate level of care days	
	Measles	Expected compared to actual stay	
	Tuberculosis		
	HIV		
	Chlamydia		
	Pneumonia and influenza hospitalizations		
	Deaths due to medically-treatable diseases		
	Ambulatory care sensitive conditions		

Community and Health System Characteristics	
Population count	CABG rates
Teen pregnancy/ teen births	Hip replacement
Expenditures per capita	Knee replacement
Doctors and nurses per capita	Hysterectomy
Hospital days per capita (possibly by duration of stay)	Myringotomy

APPENDIX C
(Adapted from the CIHI Health Indicator set)

Health Indicators
Definitions and Data Sets

1.0 Health Status

1.1 Deaths

1.1.1 Infant Mortality

Definition: Number of infants who die in the first year of life, expressed as a rate per 1000 live births.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.2 Perinatal Deaths

Definition: Annual number of stillbirths (28 or more weeks) and early neonatal deaths (deaths in the first week of life) per 1,000 total births.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.3 Life Expectancy

Definition: An estimate of the average number of years that a person born in that year is expected to live, based on current mortality rates, males, females and total.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.4 Circulatory Deaths

Definition: Age/sex standardized rate of deaths from circulatory diseases per 100,000 population, ischemic heart disease, stroke, other circulatory diseases, and total.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.5 Cancer Deaths

Definition: Age/sex standardized rate of deaths from cancer per 100,000 population, for all cancers and for specific sites (lung, breast, prostate, colorectal, cervical, malignant melanoma).

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.6 Respiratory Deaths

Definition: Age/sex standardized rate of deaths from respiratory disease per 100,000 population, for pneumonia and influenza, chronic respiratory disease, asthma, other respiratory diseases, and total.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.7 Suicide

Definition: Age/sex standardized rate of suicide deaths per 100,000 population.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.8 Unintentional Injury Deaths

Definition: Age/sex standardized rate of deaths from unintentional injuries per 100,000 population. The term unintentional ("accidental") injuries includes injuries due to causes such as motor vehicle collisions, falls, drowning, burns and poisonings.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.9 Pertussis Deaths

Definition: Number of deaths due to pertussis (whooping cough).

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.10 AIDS Deaths

Definition: Number of deaths due to AIDS and HIV infections and rate per 100,000 population (age/sex standardized).

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.11 Potential Years of Life Lost (< 75)

Definition: Age standardized potential years of life lost for males and females, for call causes and for selected preventable causes. PYLL (under age 75) is the number of years of life "lost" when a person dies "prematurely" – before age 75. A person dying at age 25, for example, has lost 50 years of life (75-25=50 PYLL).

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.1.12 Inequalities in Life Expectancy

Definition: Difference in average health status between the top and bottom thirds of the population ranked by household income. Health status could be measured by life expectancy, health expectancy, infant mortality, self-rated health, or other health status measures.

Source: Death Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

1.2 **Health Conditions**

1.2.1 Overweight

Definition: Proportion of the population who are overweight to the point of probable risk (or Body Mass Index of 27.0 or greater)

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

1.2.2 Arthritis

Definition: Proportion of the population who report that they have been diagnosed by a health professional as having arthritis.

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

1.2.3 Diabetes

Definition: Proportion of the population who report that they have been diagnosed by a health professional as having diabetes.

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

1.2.4 Asthma

Definition: Proportion of the population who report that they have been diagnosed by a health professional as having asthma.

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

1.2.5 Chronic Pain

Definition: Proportion of the population who answered "no" when asked if they were usually free of pain or discomfort. Severity of pain (mild, moderate, severe) and the degree of activity limitation are also measured.

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

1.2.6 Depression

Definition: Proportion of the population who show symptoms of depression, based on their responses to a set of questions that establishes the probability of suffering a "major depressive episode."

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

1.2.7 Injury Hospitalizations

Definition: Rates of hospitalizations due to injuries, by age group.

Source: Work Injuries Database, Occupational Health and Safety Division, Department of Employment and Labor Relations, Government of Newfoundland and Labrador

1.2.8 Food and Waterborne Diseases

Definition: The number of cases of enteric infections reported in a given year, expressed as a rate per 100,000.

Source: Communicable Disease Control Database, Department of Health and Community Services, Government of Newfoundland and Labrador

1.3 **Activity Limitation**

1.3.1 Functional Health

Definition: Proportion of the population reporting moderate or more severe functional problems, according to the Comprehensive Health Status Measurement

System, based on 8 dimensions of functioning (hearing, seeing, communicating, mobility, dexterity, pain, cognition and emotion).

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

1.3.2 Disability-Days

Definition: Proportion of the population who stayed in bed or cut down on normal activities because of illness or injury, on one or more days in the past two weeks.

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

1.3.3 Activity Limitation

Definition: Proportion of the population who report having a disability or handicap or being limited in certain activities on a continuing basis because of a health problem.

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

1.3.4 Health Expectancy

Definition: Life expectancy weighted at each age to account for levels of health status over the life course.

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

1.4 Well-being

1.4.1 Self-rated Health

1.4.2 Self-rated Health 'Excellent' Health for 2 Consecutive Years

Definition: Self-rated Health: Percent who rate their own health status as "excellent" or "very good" at any given time. Self-rated Health Over a Two-Year Period: Percent who rate their own health status as "excellent" or "very good" for two consecutive survey cycles.

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

1.4.3 Self-esteem

Definition: Proportion of the population who have a "high" sense of self-worth, based on a standard scale for this measure.

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

1.4.4 Mastery

Definition: Proportion of the population who have a high sense of mastery, based on a standard scale for this measure.

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

2.0 Non-Medical Determinants of Health

2.1 Health Behaviors

2.1.1 Smoking Rate

2.1.2 Youth Smoking Rate

Definition: Proportion of the population who are current smokers, all persons age 12 and older and youth ages 12-19. Current smokers are those who smoke on either a daily or an occasional basis.

Source: Labrador Inuit Regional Health Survey, 1997

2.1.3 Smoking Initiation (average age)

Definition: The average age at which smokers begin smoking.

Source: Labrador Inuit Regional Health Survey, 1997

2.1.4 Regular Heavy Drinking

Definition: Proportion of current alcohol drinkers are 12 and over who report having had five or more drinks on one occasion, 12 or more times in the previous year.

Source: Labrador Inuit Regional Health Survey, 1997

2.1.5 Physical Activity

Definition: Proportion of the population age 12 and older who are physically active, based on their responses to questions about the frequency, duration and intensity of their participation in leisure-time physical activity.

Source: Labrador Inuit Regional Health Survey, 1997

2.1.6 Breastfeeding

Definition: Proportion of infants aged 3 months to 3 years who are currently breastfed or who were breastfed for at least three months.

Source: Community Profiles, Labrador Inuit Health Commission (LIHC)

2.2 Living and Working Conditions

2.2.1 High School Graduation

Definition: Proportion of the population age 25-29 who have a high school graduation certificate or higher, based on the Census questions about educational attainment.

Source: High School Transcript Information System, Provincial Department of Education, Research Statistics and Planning Division

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2.2.2 Post-Secondary Graduation

Definition: Proportion of the population age 25-54 who have a post-secondary certificate, diploma or degree of some type, based on the Census questions about educational attainment.

Source: Training and Education Database, Labrador Inuit Association (LIA)

2.2.3 Unemployment Rate

Definition: Proportion of the labor force age 15 and older who did not have a job during the reference period.

Source: Labrador Inuit Regional Health Survey, 1997

2.2.4 Long-term Unemployment

Definition: Proportion of the labor force age 15 and older who did not have a job during the current or preceding year.

Source: Labrador Inuit Regional Health Survey, 1997

2.2.5 Youth Unemployment

Definition: Proportion of the labor force age 15-24 who did have a job during the reference period.

Source: Labrador Inuit Regional Health Survey, 1997

2.2.6 Low Income Rate

Definition: Proportion of persons in economic families and unattached individuals with incomes below the Statistics Canada low-income cut-off (LICO) point. The cut-offs represent levels of income where people spend disproportionate amounts of money for food, shelter and clothing. LICO's are set at income levels differentiated by family size and degree of urbanization; cut-offs are updated to compensated for changes in the consumer price index.

Source: Census, Statistics Canada

2.2.7 Children in Low Income Families

Definition: Proportion of children under age 18 living in economic families with incomes below the Statistics Canada low-income cut-off (LICO) point.

Source: Census, Statistics Canada

2.2.8 Income Inequality

Definition: The income share of the bottom half (poorest) families.

Source: Census, Statistics Canada

2.2.9 Housing Affordability

Definition: Proportion of households spending more than 30% of total household income on shelter costs, renter households, homeowners, and total.

Source: Census, Statistics Canada

2.2.10 Crime Rate

Definition: The number of Criminal Code offences expressed as a rate per 100,000 population, for violent crimes, property and other crimes, and total. Violent crimes are "person offences," which include homicide, attempted murder, sexual and non-sexual assault, abduction, and robbery. The crime rate is based on the number of incidents reported to or by the police.

Source: Police Information Retrieval System (PIRS)

2.2.11 Youth Crime Rate

Definition: The number of youth age 12-17 years charged with Criminal Code offences against a person, expressed as a rate per 100,000 youth, for violent crimes, property and other crimes, total.

Source: Police Information Retrieval System (PIRS)

2.2.12 Decision-Latitude at Work

Definition: Proportion of workers who say they have a degree of control over their work circumstances (who agree or strongly agree with the statement that "I have a lot to say about what happens at my work").

Source: National Population Health Survey, Statistics Canada

2.3 Personal Resources

2.3.1 School Readiness

Definition: Proportion of children who are "ready for school," based on the Peabody Picture Vocabulary Test, which measures verbal ability of four and five-year olds.

Source: Student Information System, Labrador School Board

2.3.2 Social Support

Definition: Proportion of the population age 12 and older who report a high level of social support, based on their responses to four questions about having someone to confide in, someone they can count on in a crisis, someone they can count on for advice, and someone who makes them feel loved and cared for.

Source: Labrador Inuit Regional Health Survey, 1997

2.3.3 Life Stress

Definition: Proportion of the population age 18 and older who report a high level of chronic stress, based on their responses to a series of 18 questions about daily life.

Source: Labrador Inuit Regional Health Survey, 1997

2.4 Environmental Factors

Indicators to measure environmental factors are under development.

3.0 Health System Performance

3.1 Acceptability

3.2 Accessibility

3.2.1 Influenza Immunization, 65+

Definition: Proportion of the population age 65 and older who report that they received a dose of influenza vaccine in the last year.

Source: Regional Immunization Database, Communicable Disease Control Office, Health Labrador Corporation (CDC)

3.2.2 Screening Mammography, Women Age 50-69

Definition: Proportion of women age 50-69 who report receiving screening mammograms within the last two years.

Source: Non-Insured Health Benefits (NIHB) Patient Statistics, Labrador Inuit Health Commission
Newfoundland Center for Health Information (NLCHI)

3.2.3 Pap Smears, Women Age 18-69

Definition: Proportion of women age 18-69 who report having had a Pap test within the last three years.

Source: Community Clinic and Hospital Registries, Health Labrador Corporation (HLC)

3.2.4 Childhood Immunizations

Definition: Proportion of children who, by their second birthday, have been fully immunized against diphtheria, pertussis, tetanus, Haemophilus influenzae type b (Hib), measles, mumps and rubella.

Source: Regional Immunization Database, Health Labrador Corporation (HLC)

3.3 Appropriateness

3.3.1 Vaginal Birth After Cesarean

Definition: Proportion of women who have previously received a cesarean section who give birth via a vaginal delivery in an acute care hospital.

Source: Newfoundland Center for Health Information (NLCHI)

3.3.2 Breast Conserving Surgery

Definition: Proportion of female breast cancer surgery inpatients in acute care hospitals who received breast conserving surgery.

Source: Newfoundland Center for Health Information (NLCHI)

3.3.3 Cesarean Sections

Definition: Proportion of women delivering babies in an acute care hospital who received cesarean sections.

Source: Newfoundland Center for Health Information (NLCHI)

3.4 Competence

3.5 Continuity

3.6 Effectiveness

3.6.1 Quitting Smoking

Definition: Proportion of smokers who quit smoking in the past two years (those who reported being "current smokers" in 1994-95 and "former smokers" in 1996-97).

Source: Labrador Inuit Regional Health Survey (LIRHS), 1997

3.6.2 Low Birth-weight

Definition: Proportion of live births with a birth-weight less than 2500 grams.

Source: Birth Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

3.6.3 Pertussis

Definition: Number of cases of pertussis reported in a given year, expressed as a rate per 100,000 population.

Source: Communicable Disease Control Database, Department of Health and Community Services, Government of Newfoundland and Labrador

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3.6.4 Measles

Definition: Number of cases of measles reported in a given year, expressed as a rate per 100,000 population.

Source: Communicable Disease Control Database, Department of Health and Community Services, Government of Newfoundland and Labrador

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3.6.5 Tuberculosis

Definition: Number of new cases of tuberculosis reported in a given time period, expressed as a rate per 100,000 population.

Source: Regional Tuberculosis Database, Health Labrador Corporation (HLC)

3.6.6 HIV

Definition: Number of new positive HIV cases in a given year, expressed as a rate per 100,000 population. Information is based on those who are tested for HIV.

Source: Communicable Disease Control Database, Department of Health and Community Services, Government of Newfoundland and Labrador

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3.6.7 Chlamydia

Definition: Number of new cases of chlamydia reported in a given year, expressed as a rate per 100,000 population.

Source: Communicable Disease Control Database, Department of Health and Community Services, Government of Newfoundland and Labrador

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3.6.8 Pneumonia and Influenza Hospitalizations

Definition: Age/sex standardized acute care hospitalization rates for pneumonia and influenza, per 100,000 population age 65 and older.

Source: Newfoundland Center for Health Information (NLCHI)

3.6.9 Deaths due to Medically-Treatable Diseases

Definition: Deaths due to medically-treatable diseases according to Charlton's definition, which is based on mortality, in specific age groups, that could potentially be avoided through appropriate medical attention.

Source: Canadian Vital Statistics, Statistics Canada

3.6.10 Ambulatory Care Sensitive Conditions

Definition: Age/sex standardized inpatient acute care hospitalization rate for conditions where appropriate ambulatory care prevents or reduces the need for hospitalization.

Source: Newfoundland Center for Health Information (NLCHI)

3.7 Efficiency

3.7.1 Surgical Day Case Rates

Definition: Day surgery cases as a percent of total surgery cases (inpatient or outpatient) that could potentially have been treated in an outpatient setting. Inpatient cases that are not generally considered candidates for day surgery, such as obstetrics patients who delivered and patients with a length of stay longer than 3 days, are excluded.

Source: Newfoundland Center for Health Information (NLCHI)

3.7.2 May Not Require Hospitalization

Definition: Percentage of acute care inpatient hospitalizations classified as May Not Require Hospitalization (MNRH). These Case Mix Groups identify groups of patients whose characteristics often allow ambulatory treatment not requiring admission.

Source: Newfoundland Center for Health Information (NLCHI)

3.7.3 % Alternate Level of Care Days

Definition: Percentage of inpatient days where a physician (or designated other) has indicated that a patient occupying an acute care hospital bed was well enough to have been cared for elsewhere.

Source: Newfoundland Center for Health Information (NLCHI)

3.7.4 Expected Compared to Actual Stay

Definition: Average days for "typical" acute care inpatients over/under the Expected Length of Stay (ELOS) Patients. ELOS depend on their Case Mix Group assignment, as well as complexity levels and age where appropriate. Typical cases exclude deaths, transfers, voluntary sign-outs, and cases where the actual length of stay is greater than the "trim point" established by CIHI.

Source: Newfoundland Center for Health Information (NLCHI)

3.8 Safety

3.8.1 Hip Fractures

Definition: Age/sex standardized acute care hospitalization rates for fracture of the hip, per 100,000 population age 65 and older.

Source: Newfoundland Center for Health Information (NLCHI)

4.0 Community and Health System Characteristics

4.1 Population Count

Definition: The number of people living in a geographic area by age and sex.

Source: Administrative Enumeration System, Labrador Municipal Councils

4.1.2 Teen Pregnancy/Teen Births

Definition: The estimated number of pregnancies (or births) per 1,000 women age 15-19. The estimate is based on the number of pregnancies resulting in live births, stillbirths, or induced (therapeutic) abortions.

Source: Birth Books, Public Health Department, Labrador Inuit Health Commission (LIHC)

4.1.3 Expenditures per Capita

Definition: Health expenditures per capita, for expenditures in the public sector, private sector, and total.

Source: Non-Insured Health Benefits (NIHB), Labrador Inuit Health Commission Newfoundland Center for Health Information (NLCHI)

4.1.4 Doctors and Nurses per Capita

Definition: Active civilian general practitioners or family practitioners per 100,000 population; Active civilian medical specialists per 100,000 population; Registered nurses working in nursing per 100,000 population.

Source: Newfoundland Center for Health Information (NLCHI)

4.1.5 Hospital Days per Capita

Definition: Total number of patient-days spent in acute care hospitals, expressed as a rate per 1,000 population (age-sex standardized).

Source: Newfoundland Center for Health Information (NLCHI)

4.1.6 CABG Rates

Definition: Age/sex standardized rate of coronary artery bypass graft surgery performed on inpatients in acute care hospitals per 100,000 population.

Source: Newfoundland Center for Health Information (NLCHI)

4.1.7 Hip Replacement

4.1.8 Knee Replacement

Definition: Age/sex standardized rate of total hip or knee replacement surgery (unilateral or bilateral) performed on inpatients in acute care hospitals per 100,000 population.

Source: Newfoundland Center for Health Information (NLCHI)

4.1.9 Hysterectomy

Definition: Age standardized rate for hysterectomies provided to inpatients in acute care hospitals, per 100,000 women age 20 and older.

Source: Newfoundland Center for Health Information (NLCHI)

4.1.10 Myringotomy

Definition: Fee-for-service billings for myringotomies performed by physicians in a given area per 100,000 population.

Source: Newfoundland Center for Health Information (NLCHI)

APPENDIX D

Data Quality and Practicality Rating Scores, with Total Data Rating Scores for Data Sources Remaining after the Elimination Process

Data Source	Quality Rating Score	Practicality Rating Score	Total Data Rating Score
NIHIB Patient Statistics	31/35 (88.57%)	31/35 (88.57%)	62/70 (88.57%)
Public Health Death Books	35/35 (100%)	31/35 (88.57%)	66/70 (94.29%)
Public Health Birth Books	35/35 (100%)	31/35 (88.57%)	66/70 (94.29%)
Community Profiles	25/35 (71.43%)	29/35 (82.86%)	54/70 (77.14%)
Mental Health Databases	22/35 (62.86%)	26/35 (74.29%)	48/70 (68.57%)
Labrador Inuit Regional Health Survey	23/35 (65.71%)	30/35 (85.71%)	53/70 (75.71%)
LIA Post Secondary Student Support Program (PSSSP)	27/35 (77.14%)	30/35 (85.71%)	57/70 (81.43%)
LIA Training and Education Database	23/35 (65.71%)	30/35 (85.71%)	53/70 (75.71%)
LIA Membership List	23/35 (65.71%)	29/35 (82.86%)	52/70 (74.29%)
Provincial Communicable Disease Control (CDC) Database	34/35 (97.14%)	34/35 (97.14%)	68/70 (97.14%)
Provincial Immunization Database	27/35 (77.14%)	26/35 (74.29%)	53/70 (75.71%)
Regional Immunization Database	27/35 (77.14%)	26/35 (74.29%)	53/70 (75.71%)
Regional TB Database	23/35 (65.71%)	28/35 ((80%)	51/70 (72.86%)
Provincial TB Registry	25/35 (71.43%)	26/35 (74.29%)	51/70 (72.86%)
Hard copy records of clinic and home visits	25/35 (71.43%)	23/35 (65.71%)	48/70 (68.57%)

Data Source	Quality Rating Score	Practicality Rating Score	Total Data Rating Score
Hard copy records of hospital emergency visits, laboratory and radiology utilization	24/35 (68.57%)	23/35(65.71%)	47/70 (67.14%)
Breast feeding database	18/35 (51.43%)	26/35 (74.29%)	44/70 (62.86%)
Work Injuries database	24/35 (68.57%)	28/35 (80%)	52/70 (74.29%)
Police Information Retrieval System (PIRS)	30/35 (85.71%)	34/35 (97.14%0	64/70 (91.43%)
Simplified Paperless Universal Reporting System (SPURS)	30/35 (85.71%)	34/35 (97.14%)	64/70 (91.43%)
Population demographics (Statistics Canada)	25/35 (71.43%)	27/35 (77.14%)	52/70 (74.29%)
Persons Joined in Holy Matrimony	35/35 (100%)	31/35 (88.57%)	66/70 (94.29%)
Persons Departed this Life	35/35 (100%)	31/35 (88.57%)	66/70 (94.29%)
National and provincial health related reports (CIHI)	25/35 (71.43%)	32/35 (91.43%)	57/70 (81.43%)
Cancer Registry	23/35(65.71%)	33/35 (94.29%)	56/70 (80%)
Student Information	21/35 (60%)	33/35 (94.29%)	54/70 (77.14%)
High School Transcript Information System	27/35 (77.14%)	33/35 (94.29%)	60/70 (85.71%)
Provincial and regional health related reports (NLCHI)	25/35 (71.43%)	34/35 (97.14%)	59/70 (84.29%)
Taxation listing and Municipal enumeration	26/35 (74.29%)	30/35 (85.71%)	56/70 (80%)
Births, Deaths and Marriages (Vital Statistics)	24/35 (68.57%)	30/35 (85.71%)	54/70 (77.14%)

LABRADOR INUIT
HEALTH COMMISSION

HEAD (
P.O. Bo
North W
A0P 1M

(709) 497-8356 / 8371 / 8353 / 8532
(709) 896-9422
Fax: (709) 497-8311

Appendix E

LABRADORIMI INUIT
INOSITSIAGITTOTIGASUALLUGIT
KAMAJET

SULIAKAPVILAGINGA
P.O. Box 234
North West River-Rimi, Labradorimi
A0P 1M0

(709) 497-8356 / 8371 / 8353 / 8532
(709) 896-9422
Aullatitsiutinga: (709) 497-8311

February 8, 1999

SAPUTJIVIK
(TREATMENT CENTRE /
IKAJUTTAUVIK)
North West River/
North West River-Rimi
Labrador
A0P 1M0
(709) 497-8509 / 8514

MELVILLE HOSPITAL
MELVILLE-LIUP
ANNIASIUPVINGANI
Goose Bay/Goose Bay-Mi
Labrador, A0P 1S0
(709) 896-6827
Fax: (709) 896-2581

HAPPY VALLEY /
HAPPY VALLEY-MI
Box 70, Station 'B'
Labrador, A0P 1E0
(709) 896-3396 / 4055
Fax: (709) 896-2519

HOPEDALE /
HOPEDALE-IMI
Labrador
A0P 1G0
(709) 933-3834 / 3894
Fax: (709) 933-3645

MAKKOVIK /
MAKKOVIMMI
Labrador
A0P 1J0
(709) 923-2340 / 2297
Fax: (709) 923 2146

NAIN /
NAIN-NIMI
Labrador
A0P 1L0
(709) 922-2114 / 2232
Fax: (709) 922-2216

POSTVILLE /
KIPUKKAMI
Labrador
A0P 1N0
(709) 479-9842 / 9878
Fax: (709) 479-9719

RIGOLET /
RIGOLET-TIMI
Labrador
A0P 1P0
(709) 947-3309 / 3328 / 3446
Fax: (709) 947-3412

Dear Ms.

Re: Health Information and Health Status Monitoring

As of course you are well aware, Northern Labrador has recently become the focus of a major mining exploration and development project. While local health and social service agencies seek to describe the health status of the people, this pending development further accentuates an already pressing need for adequate health information. Historically, health information has been sporadically gathered by various agencies, but has not been generally analyzed or shared for various reasons. With the advent of a development then, the time would seem ripe to formulate a health monitoring tool, data base and health information system that can be used as a means to appropriately assess the health status of the client base pre-development, during subsequent stages of the development and then on into the future.

With these thoughts in mind then, the Labrador Inuit Health Commission (LIHC) is currently investigating the development of a health monitoring system to review the health status of our client base over time. The major focus of such a system would be on describing the patterns of health of the residents in the Northern Labrador region. The intent of such a comprehensive profile, once developed, would be to help the community and agencies serving the community to establish and maintain a broad strategic view of its health status and the various factors which influence it and then tailor programming to meet emerging needs.

Our organization realizes that there are numerous groups in the area that have a wealth of information and as a first step in the development of a truly regional system, we are seeking to understand and be aware of the types of information

and data your organization already collects on a regular basis with regard to the clients we mutually serve.

Thus, would it be possible for your agency to provide to LIHC:

1) a general listing or outline of the kinds of information kept by your agency as a part of regular record keeping and statistics gathering;
2) an identification of the information that could be shared among agencies without breaching confidentiality;
3) an identification of gaps in current information collection that could be addressed in the development of an ongoing health status monitoring system.

Our organization is aware that this undertaking will be time consuming and will involve a great deal of coordination and effort. But, we feel that the need for information and data is essential to produce effective programs and services for the people we serve.

Please advise if your organization collects information at the community level that might be useful to the development of this health status monitoring system. I can be reached at 709-922-2185 should clarification or discussion become necessary.

Regards.

Margaret Webb

Margaret Webb
Director of Community Health Nursing
Acting Director of Community Health and Safety